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The Psychosocial Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study

by

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Dedication

This thesis is dedicated to my mother, Angela Bedingfield, whose bravery and openness in living and dying continues to guide me.

Abstract

The focus of this study is to explore psychosocial changes experienced by AIDS patients and their caregivers in Western Uganda as a result of the introduction of Highly Active Antiretroviral Therapy (HAART). Fifty four individual interviews were completed with 14 HAART patients and their caregivers. Four focus groups were also conducted with male and female, patients and caregivers. Placing individuals' stories in the context of their personal and household HIV narrative was more important than anticipated. Important benefits for both patients and caregivers were: overcoming terrible fears about the patient's death; ability to have hope for the future; and becoming more resistant to social stigma. Patients and caregivers both described having to carry on in households destabilized by HIV, particularly in a financial sense. The patient's health remained fragile. This reduced the patient's financial productivity and caused the caregiver to continue to feel a sense of responsibility for the patient.

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List of Abbreviations

AIDS:	Acquired Immunodeficiency Deficiency Syndrome
ART:	Antiretroviral Therapy
ARV:	Antiretroviral
CB-ARV:	Community Based Antiretroviral Treatment for AIDS Patients Project
CD4:	Cluster of Differentiation Immune Cells
DSM:	Diagnostic and Statistical Manual of Mental Disorders
HIV:	Human Immunodeficiency Virus
HAART:	Highly Active Antiretroviral Therapy
QoL:	Quality of Life
RA:	Research Assistant
UN:	United Nations
UNAIDS:	Joint United Nations Program on HIV/AIDS
WHO:	World Health Organization

CHAPTER 1: INTRODUCTION

Highly Active Antiretroviral Treatment (HAART) is a specific combination of antiretroviral medications for those in more severe stages of HIV infection. While HAART does not cure HIV/AIDS, it has been shown to dramatically prolong life and improve quality of life in those suffering with AIDS (Parsons, Braaten, Hall & Robertson, 2006). The development of this drug regimen has given hope for the global AIDS community that some of the suffering that has been brought by this disease can be lifted. However, access to this medication is by no means equitable. In 2003, the World Health Organization (WHO) succeeded in bringing the world community's attention to the large gap that exists between high and low income countries in access to HIV antiretroviral therapy. By calling this gap "a global Public Health Emergency" (UNAIDS, 2006), the WHO rallied the world to take action. Two important goals emerged from this process. One was the "Three by Five Initiative" and the second was the commitment of the G8 to Universal Access to HIV treatment by 2010 (UNAIDS, 2008). The purpose of the "Three by Five Initiative" was to have three million people in low and middle income countries in treatment by the year 2005. Unfortunately, the goal for "Three by Five" was not met. At present, donor countries have not fulfilled the funding commitments which are required in order to meet the G8's 2010 goals.

Despite the fact that the world community has fallen short of these goals, the attention garnered by them has succeeded in dramatically improving access to treatment. Since 2003, the number of people in sub-Saharan Africa receiving antiretroviral treatment has increased tenfold (UNAIDS, 2006, pg 10) and some relief from the scourge of HIV/AIDS is beginning to come to those most in need. The purpose of this study was to gain a better understanding of the psychosocial impact of HAART on those taking these drugs as well as their caregivers, in a sub-Saharan African context.

1.1 Background

HAART Globally

HAART is a combination of antiretroviral medications that are given to patients with the intention of suppressing HIV for an extended period of time. This therapy is commenced when a patient's immune system begins to fail, which is often marked by a dramatic drop in CD4 cell counts and the development of opportunistic infections. The first antiretroviral medication was used against HIV in 1986. The use of these medications evolved over the following decade until the first HAART combination therapy was used in 1996 (Barnett & Whiteside, 2002, p 339). For many years after its first use, HAART was a life saving therapy used only by a privileged minority of patients. In its original incarnation, HAART was exceptionally expensive, complicated for patients to follow and required a great deal of health care infrastructure for the careful monitoring of patients. In recent years many factors have coalesced to allow HAART to be brought to the developing world. The complexity of the drug regimen has decreased substantially and side effects have been reduced (Barnett & Whiteside, 2002, p. 42 & 338). Very importantly, the political will has been created to make the cost of these drugs feasible for developing countries. This has been done by ensuring that the price of the drugs is substantially reduced and that foreign aid is made available for the purchase and delivery of these drugs. It has also been shown that HAART is a cost effective intervention for countries facing the full force of the HIV pandemic when compared to the staggering costs of not treating those with AIDS (Booysen, Van Rensburg, Bachmann. Louwagie & Fairall, 2007). These developments have brought about a dramatic increase in the accessibility of HAART in sub-Saharan Africa where more than two thirds of the global HIV positive population lives (UNAIDS, 2007, p. 7). In mid 2006, there were over one million people in sub-Saharan Africa receiving HAART (Hirsch, Parker & Aggleton, 2007).

HAART in Uganda

The HIV epidemic peaked in Uganda in the early 1990's with prevalence rates as high as 25-30% in the most affected areas amongst the sexually active population. A multilevel government commitment and a culture of openness in the country has succeeded in reducing prevalence rates to 5-10% in urban areas and below five percent in some rural areas (Ministry of Health and ORC Macro, 2006). In recent years, the downward trend in HIV rates has stabilized and there is some concern that the gains of the 1990's are being eroded (UNAIDS, 2007, p.17). To combat this, the Ugandan government changed its HIV strategy in 2003. Previously the strategy had been focused solely on prevention, specifically promoting the "ABC's"; abstinence, being faithful and using condoms. The new program is called "ABC Plus" and includes a focus on ARV provision and reducing barriers to universal access to treatment (Ministry of Health and ORC Macro, 2006; Government of Uganda, 2008, p. 25). At present there are 106,000 people on HAART in Uganda (Government of Uganda, 2008, p. 25), which is estimated by the UN to be just over 50% of the AIDS patients who are in need (UNAIDS, 2006, p. 153).

At present there are 286 sites throughout Uganda providing ART (Government of Uganda, 2008, p 26). Triomune is the combination therapy most commonly used. It is a combination of stavudine, lamivudine and nevirapine and is taken twice per day, twelve hours apart (Community Based, 2005 a). At many sites, maintaining a continuous supply of drugs is a problem and shortfalls in supply do occur (personal communications, Iruhuura Post Test Club Meeting, October 2, 2007). In an effort to combat this, Uganda is presently in the early stages of manufacturing its own triomune with the intention of maintaining a constant national supply and possibly exporting surplus medication to surrounding countries (African Chronicles, Oct 8, 2007). In order to access HAART, all Ugandan government patients must first go through a process of Voluntary Counselling and Testing to determine their HIV status. Following a positive HIV test, a patient's readiness to begin HAART is assessed using several disease staging measures, of which the most important is arguably CD4 cell counts. When this study was conducted, the CD4 level which indicated a need to commence HAART was 200 cells per μl of blood in the absence of other opportunistic infections (WHO, 2005. p.9). Once patients have started HAART, they are responsible to travel to the clinic themselves to collect their medication and also to travel to the clinic and sometimes to major centres for lab work needed to monitor the patient throughout therapy. Through formal and informal research in Kabarole District, transport costs have been shown to be a considerable barrier to patients accepting and continuing on HAART (personal communication, Iruhuura Post Test Club Meeting, October 2, 2007; Duff, 2007).

Community Based Antiretroviral Treatment for AIDS Patients Project

The CB-ARV project is the result of a collaboration between the University of Alberta, Makerere University in Kampala, Uganda and health officials in the Kabarole District. The project is working in a rural community called Rwimi which is a sub-County of Kabarole District, Western Uganda. The project is providing free treatment to approximately 185 persons living with AIDS in the area (Walter Kipp, personal communications, May 25, 2006).

One important aim of the Community Based Antiretroviral Therapy for AIDS Patients Project (CB-ARV) is to reduce some of the barriers of HAART distribution and monitoring that prohibits some patients from accessing this life saving medication. Drugs are brought to the patients' homes by use of Volunteer Health Workers and once patients are stabilized on treatment, they do not need to travel for medical attention or monitoring unless there is an unforeseen event. When the patient is started on HAART, patients must choose a "Treatment Partner" who will monitor their adherence and assist the patient to detect health problems as early as is possible. It is hoped that the findings from this project will demonstrate that treatment delivered in this fashion can be shown to be more appropriate for a resource poor setting as well as safe, effective and sustainable (Community Based, 2005 b; Arif Alibhai, personal communications, May 22, 2007).

Prior to 2006 and the commencement of the CB-ARV project, there was no access to free HAART in Rwimi sub-County. Therefore many of the early patients enrolled into the project were very ill and may have been treated earlier had the medication been available to them (Walter Kipp, personal communications, August 21, 2008).

The CB-ARV research team is also interested in exploring the wider socioeconomic impact of HAART on the community in Rwimi. To this end there are ongoing projects in the area run by the School of Public Health, Department of

Sociology and Department of Rural Economy from the University of Alberta (Community Based, 2005 b). The sample for the current study is a subset of the Community Based ARV Project. The patients and caregivers for this study will be selected from the patients of the CB-ARV project. It is expected that there will be overlap between “treatment partners” in the CB-ARV project and respondents labelled as “caregivers” for this study, but this is overlap is not thought to be of significance for the purposes of this study.

CHAPTER 2: Literature Review

While the impact of HAART on patients, families and societies has been well studied in the West, this research is still in its infancy in Africa. A search of medical and social science databases PUBMED, WEB OF SCIENCE, MEDLINE, CINAHL, SCOPUS and EMBASE with key words including; HAART, psychosocial, impact, adjustment, reintegration, economic, emotional, social, disclosure, stigma, caregiver, Africa and child, yielded only one qualitative study (Smith and Mbakwem, 2007) in an African population that focused on the emotional and social impacts of HAART on patients. There were no studies, qualitative or quantitative found which focused on the impact of HAART on caregivers. Several qualitative studies which discussed on the psychosocial impact of HIV on patients and caregivers were found.

The sole qualitative study found, focused solely on the future reproductive intentions of HAART patients. Smith and Mbakwem (2007) used ethnographic case studies to illuminate the importance of marriage and child bearing to HAART patients in Nigeria. This study followed individuals over several years to observe how patients resumed the pursuit of their reproductive "life projects". The authors found that once patients were relieved of the immediate physical threat of AIDS, the social importance of marriage and child bearing again became paramount. The study found that patients were well aware that their decision making was fraught with "ethical dilemmas, social implications and health consequences", and engaged in complex decision making around issues of disclosure, risks for infecting others and goals for the future. Patients often found that the counselling that they received was at odds with what was expected of them socially, placing them in an extremely difficult situation. The authors of the study called upon ART programs to offer counselling that acknowledged and supported how important it is for patients to resume their marital and child bearing life projects.

2.1 Impact of HAART

Studies in Western Settings

The vast majority of research undertaken to document the psychosocial component of the "Lazarus Effect" (Brashers et al., 1999) experienced by many HAART patients has been done in Europe and North America. While the populations of these studies likely have a very different social reality than sub-Saharan African HAART patients, some of the identity related issues which these patients must struggle with are universal in nature. The goal of much of the Western research in this area has been to gain an understanding of the identity challenge produced when "patients who had accepted dying now have to renegotiate living" (Grubb and Maclure, 1997 in Nixon and Renwick, 2003).

These studies have shown that HAART patients do experience a great deal of stress and uncertainty about their future as a result of taking HAART. However in most cases the optimism and increased control over one's own life outweighs the burden of these increased stresses (Haltkitis, Shrem, Zade & Wilton, 2005).

Brashers et al. (1999) focused on the psychosocial renegotiation that came about as a result of physical revival. This study found that patients needed to renegotiate their lives in four key areas; 1) feelings of hope and future orientation 2) social roles and identities 3) interpersonal relations and 4) the quality of their lives. This massive renegotiation process exposed patients to a great deal of uncertainty. This study warned that patients who fail to cope with this uncertainty may enter a state called chronic sorrow and therefore experience poorer quality of life. In this qualitative study, respondents described that the high levels of uncertainty that they experienced threatened feelings of hope and orientation towards the future. Patients described struggling with the transition from the role of a dying patient to the role of a person living with a chronic illness. Patients were somewhat fearful of their new therapy, expressing concerns about the continued efficacy and the possible side effects of the drugs. The physical revival experienced by patients allowed them to participate more often in social activities, thus exposing them to greater amounts of HIV stigma and awkward social situations. One especially difficult situation patients faced was returning to work.

The challenge of social reintegration is frequently mentioned in the Western literature in this field. One qualitative study conducted by Meystre-Agustoni, Dubois-Arber, Cochand & Telenti (2000) reported that patients felt that social reintegration after HAART was difficult or impossible. This caused patients to wonder if it was really worth so much effort to remain physically healthy when they were forced to remain socially dead.

A quantitative study by Siegel & Schrimshaw (2005) worked with two all female samples, one from the pre-HAART era and one from the post-HAART era. Surprisingly, this study found that women in the post-HAART era experienced more psychosocial distress. Women in the post-HAART era were more likely to report health related stress and stress from stigma and disclosure issues. They were also more likely to use maladaptive coping than their pre-HAART counterparts. The authors of this study encouraged those running HIV counselling programs not to assume that the physical recovery produced by HAART reduced patients need for supportive counselling.

In another qualitative study, Klitzman et al. (2004) elaborated on the social ambivalence created for HAART patients, especially as related to stigma and disclosure. The physical changes produced by HAART were advantageous socially in that they allowed patients to look and feel well which made going out in the community a possibility. However, this increased contact with others also allowed more opportunities for one's HIV status to become known, which in turn increased opportunities for HIV stigma to be felt. Conversely, this study also found that physical changes allowed patients to more readily conceal their HIV status when that was advantageous for them.

Patients disclosed their HIV status strategically. They described revealing their HIV status in order to protect others and gain respectability and support. Patients were motivated to conceal their HIV status when they were afraid of rejection, wanted to protect others from emotional distress or when they felt shame or dependency. In this way and others, HAART can both increase and decrease the positive social support experienced by the patient.

The psychosocial ambivalence created by HAART was also echoed in the study by Halkitis et al. (2005). Respondents in this study were very proud of their improved appearances, increased energy levels and the amount of control over their lives they had regained, however anxiety was also increased. Anxiety was related to managing the drug regimen and financial and social matters. Ultimately this study found that patients were able to successfully change their focus from dying to living. While this change in focus was stressful, most patients were hopeful for the future and motivated to make positive changes.

Quality of Life Studies in sub-Saharan Africa

Quality of Life (QoL) studies done with African HAART patients have found more positive results than Western Studies in the psychosocial realm, however being quantitative in nature, this method of study does not allow patients to express the complexity of their experiences (Brandt, Dawes & Bray, 2006). In a cross-sectional study in the Free State in South Africa, Booysen, Van Rensburg, Bachmann, Louwage and Fairall (2007) compared QoL scores from patients who had commenced ART to those awaiting treatment. The study found that the commencement of ART was associated with significant improvements the variables of; global happiness, life satisfaction and physical and emotional wellbeing. Booysen et al. (2007) found duration of therapy to be a very important factor in their analysis. Improvement in physical and emotional wellbeing increased a great deal for the first three months, then dissipated over time. However improvement in the life satisfaction variable did not start until after three months duration.

A similar South African study in the Free State by Wouters, Meulemans, Motlemans, Van Rensburg & Heunis (2007) echoed the findings of the previous study. This study also found that ART was associated with increased life satisfaction and happiness and that the early months on ART are responsible for the majority of these gains. ART patients in this study had significantly fewer problems with self care, mobility and daily activities than the control group. The work of this team also found a reduction in anxiety and depression. ART was found to produce improvements in emotional wellbeing both indirectly through improvements in physical well being and independently.

Jelesma, Maclean, Hughes, Tinse and Darder (2005) also found that HAART patients were significantly less depressed and anxious. They also found that patients receiving HAART were more able to care for themselves and complete their normal activities. Importantly this study was also demonstrated that drug side effects had little effect on patient's Health Related Quality of Life.

One QoL study completed in rural, eastern Uganda (Stangl, Wamai, Mermin, Awor & Bunnell, 2007) showed that the findings of the above South African studies also held in this setting. This study again found that the major improvements occurred in the first three months and that improvements seemed to level off between nine and 12 months. Interestingly this study found that the only independent predictor for QoL at 12 months was economic dependence on others before commencing HAART. Economically dependant patients showed significantly less improvement in their physical and mental wellbeing after other factors were controlled for. The authors felt this indicated that HAART patients' QoL could be improved by integrating financial assistance programs into medication distribution programs.

Effect of HAART on Economic Activity

While HAART patients are likely in a much better economic position as a result of their physical recovery, it is very likely patients remain concerned about their financial wellbeing. In their article based on lengthy personal experience in rural Uganda; Russell, Seely, Ezati, Wamai, Were & Bunnell, (2007) explain what they believe are the serious economic challenges faced by HAART patients after they "come back from the dead". HIV infection is very often financially devastating for patients and their families and in most cases; it is beyond the ability of HAART patients to fully recover. In this article, Russell et al. describe that HAART patients need assistance in order to successfully adjust and "normalize" their lives with this chronic illness.

This call for support by Russell et al. (2007) is supported by Rosen, Ketlhapile, Sanne & Bachman Desilva (2008) who examined economic productivity amongst HAART patients in South Africa. This study found that HAART patients were almost half as likely to report functional impairment in the last week when compared to their AIDS sick, non-HAART counterparts. However, HAART patients still reported a functional impairment level of 32%. Patients reported being unable to work an average of almost one day per week. This indicates that despite physical improvements, HAART patients were still unable to work as well as they could when they were healthy, making them economically disadvantaged. The authors of this study felt that economic productivity was better measured by ability to complete normal activities than participation in wage employment since formal employment rates in this rural area of South Africa were normally very low.

This study by Rosen et al. built upon a previous study from Kenya (Larson et al., 2008) which showed that the number of hours worked rose by 35% when tea plantation workers living with AIDS started HAART. Together these studies show that while patients' economic wellbeing is greatly improved by accessing treatment, economic wellbeing remains a significant problem that patients must overcome in order to have a successful future for themselves and their family.

One qualitative study from Uganda (Crane et al., 2006) which focused on patients' motivation to adhere to their drug regimen, betrayed some information regarding patient's hopes for the future. Patients were motivated to adhere to their medication regimens in order stay alive to benefit their families. Patients hoped to establish financial security for their children before they died.

Effect of HAART on Social Support

The wellbeing of HAART patients is dependant on the highly interrelated concepts of social support, stigma and HIV status disclosure. While there is a great deal of variation in the results of studies in this complex area, there is general agreement that African patients disclose their HIV status in a systematic way. In disclosing their status, patients attempt to gain support for themselves and minimize their exposure to rejection, discrimination and stigmatization (Brandt, Dawes & Bray, 2006; Chenard, 2007 in Ncama et al., 2008; Skogmar et al., 2006).

Two studies from South Africa and one study from Botswana suggest that issues related to HIV stigma and HIV status disclosure remain a significant problem for people living with HIV after the commencement of HAART.

One study carried out in Kwazulu-Natal (Ncama et al., 2008) emphasized the importance of social support when coping with chronic illness. This cross sectional, quantitative survey found that the ART patients in their study identified social functioning within a context of stigma to be amongst their greatest concerns. The findings of this study also showed that patients struggled most in areas related to social functioning and mental health.

These findings were supported by Wolfe et al. (2006) in Botswana who found that concerns about stigma were widespread amongst the patients in their study, who had been on ART longer than three months. This study found that 30% of respondents felt that HIV severely affected their personal relationships. Patients were careful about how they disclosed their status. In this study, 94% of respondents kept their status a secret from their community, 69% withheld their status even from their family and 12% of respondents told no one about their HIV status. Thirty seven percent of patients in this study felt that the social problems associated with being HIV positive were more severe than the medical problems, compared to 30% who felt that the reverse was true.

In Johannesburg, Skogmar et al. (2006) found that ART had no affect on the frequency of status disclosure by patients or the patterns of this disclosure. In this study, patients on treatment were compared to those not on treatment and no significant disclosure differences were found. This indicates that patients still feel that there are disadvantages to being known as HIV positive, despite being on treatment.

The lone study on social support and HAART in Uganda documented more optimistic findings. Apondi et al. (2007) measured the frequency of positive and negative social outcomes amongst patients in a Home Based AIDS Care project in rural Uganda. This prospective study found that HAART patients experienced a social benefit from treatment. When patients' responses were compared at baseline and after three months on HAART, patients reported significant increases in community support, family support and relationship strengthening. Importantly, this study also measured changes in negative social experiences and found that HAART did not increase the incidence of events such as marital break up, domestic abuse, isolation or discrimination.

2.2 Impact of HIV: Context for HAART Changes

A great deal has been written about the overwhelming economic, psychological and social impact of the HIV epidemic on sub-Saharan Africa. Researchers have postulated whether measuring impact at the individual level, the household level, the level of the social network, or higher best captures the full devastation of this epidemic. While this study is meant to measure the impact of HAART at the individual level, an awareness of the context for individual experience is imperative for a complete understanding. An important piece of context for every individual's experience with HAART is that person's HIV history as well as that person's family and community environment. The importance of context is espoused by Brandt, Dawes & Bray (2006) who reported that the experience of the female HAART patients in their study could not be adequately represented unless the context of their family, neighbourhood, medical and financial histories were also described. Therefore in order to better understand the psychosocial impact of HAART, a brief review of the literature describing the psychosocial impact of HIV at various levels also seems appropriate in order to provide context. However this discussion will not attempt to cover the full range of literature in this area which is vast. This discussion of HIV impact will focus on HIV caregivers as there is no literature related to HAART and caregivers to provide background for this study.

Impact of HIV on Caregivers

The literature which illuminates the emotional and social wellbeing of AIDS caregivers in Africa paints an especially bleak picture. The vast majority of these caregivers are female (Orner, 2006; Kipp, Tindyebwa, Karamagi & Rubaale, 2006; Matukala Nkosi, Kipp, Laing & Mill, 2006). However Kipp et al. (2006) found that in

Uganda, the incidence of male care giving is increasing due to a lack of women to fulfill this role. Where males were acting as caregivers, the burden placed on them by providing this care was equal to their female counterparts.

All studies reported that caregivers experience an enormous amount of stress with very few supports to aid them in coping (Kipp et al., 2006; Matukala Nkosi et al. 2006; Katapa, 2004). Descriptors such as isolating, debilitating (Kipp et al., 2006), overwhelming, despair, and loneliness (Orner, 2006) were used frequently in the literature to describe the experiences of these individuals. Stress is experienced by caregivers because they must be responsible for the often all consuming work of tending to the sick individual, all of the other household work that the caregiver would normally be responsible for, as well as the work that the sick individual would have done (Orner, 2006). All of this must be done in an environment of economic scarcity where basic needs often cannot be met (Rajaraman, Russell & Heymann, 2006; Kipp et al., 2006).

The caregiver is not supported in his or her role for several reasons. Informal support is usually not offered because HIV stigma often affects the entire household (Kipp et al., 2006; Matukala Nkosi et al. 2006; Katapa, 2004) and formal support programs in Africa often do not consider the needs of the caregiver (Matukala Nkosi et al., 2006). The extreme stress created by the illness often strains relationships inside the household, which weakens relationships within the family (Urduang, 2006).

Two studies specific to Uganda shed some light on the concerns of older female caregivers. Very often, elder women have their adult children return to their home when their children are very sick with AIDS, bringing with them the grandchildren of the caregiver. This places extremely high demands on the caregiver (Ssengonzi, 2007). The caregiver feels obligated to care for both their child and grandchildren because of family connections and is often alone in this role (MacNeil, 1996). Many caregivers worry about the future. Who will care for them when they get older (Ssengonzi, 2007)? How will they care for their grandchildren in their old age with limited income (MacNeil, 1996)? These studies showed that care giving work challenged carers emotionally, economically and physically.

Female headed households are not uncommon in Africa and are doubly vulnerable to the harms of excessive care burden when affected by AIDS (Brandt et al., 2006). In many cases, children are left to care for their mothers after their father has died of AIDS. It has been shown that Ugandan children who have lost one or more parent to AIDS, have higher rates of depression, anxiety and anger than children who had not lost a parent to HIV (Atwine, Cantor-Graae & Banjunirwe, 2005). Not only are children in these households scarred by the death of their father, but they are again traumatized by the care giving they must do when their mothers' become ill. These children face all of the stress and grief experienced by adult caregivers, but with fewer resources to cope (Robson, Ansell, Huber, Gould & van Blerk, 2006). Children are often withdrawn from school in order to do this care work and are further isolated from their friends because the demanding nature of their work keeps them at home. Children must also cope with the guilt and pain of seeing other siblings poorly cared for.

It is obvious with all caregivers, but especially with children that there is a great deal of potential for HAART to lighten their heavy load. In fact, Kaler (personal communications, May 2007) has found that all household members, especially children, experience psychosocial improvement as a result of the patient receiving therapy.

Impact of HIV on Patients

Makoae et al. (2005) carried out a survey in South Africa to explore the subjective symptoms experienced by HIV patients and which of these symptoms patients found most bothersome. Importantly this study included both physical and psychological symptoms. This study found that patients suffered a great deal from numerous symptoms. Symptoms tended to be clustered in groups, with the average patient reporting 17.5 complaints. The five most frequently reported symptoms were; fatigue, weakness, weight loss, fear, worries and painful joints. This study found that not only did patients suffer very many physical symptoms in the absence of any palliation, but also experienced severe psychological distress. Patients who reported inadequate incomes were more likely to report higher numbers of symptoms than those with adequate incomes.

In order to gain an understanding of the mental health experience of Ugandan HIV sufferers, Wilk and Bolton (2002) used qualitative methods to explore local perceptions. The aim of this study was to explore the thoughts of Rakai District residents on the mental health impacts of HIV and to compare these reports to Western constructs of mental illness. The individuals sampled for this study named eight psychological symptoms, which could be grouped into two locally known syndromes; Yo'kwekyawa and Okwekubaziga. Yo'kwekyawa can be translated as hating ones self and included suicidal ideation and apathy regarding life. Okwekubaziga is translated as pitying one's self and has sadness as a prominent feature. Both the psychological effects of HIV and the syndromes listed by respondents had features in common with the DSM diagnosis of depression. This study confirmed that in this area of Uganda, residents recognized depression and felt that it is associated with HIV infection.

Impact of HIV on Households

It has been well documented that economic, social and physical effects of an individual's HIV infection does not only affect that individual, but all the members of that individual's household. Reciprocally, it has also been shown that individual experiences are also influenced by household level factors. As was previously mentioned, Makoae et al. (2005) found that people living with HIV suffered with more numerous symptoms when they lived in situations of economic scarcity. Similarly one of the primary concerns of overburdened caregivers is how to manage all the needs of the household under very difficult conditions. What worsens the interaction of household level and individual level effects is the fact that HIV is sexually transmitted. Households are often repeatedly affected and these economic and psychological effects tend to be cumulative (Hosegood, Preston-Whyte, Busza, Moitse & Timaeus, 2007).

Families affected by HIV are often in flux and this creates hardship for the members of these households. While several studies have shown that AIDS causes drastic alteration in household organization, very few studies have been able to show conclusive trends in terms of dependency rates and household size (Madhavan & Schatz, 2007; Barnett & Whiteside, 2002). Madhavan and Schatz (2007), in their study in rural South Africa, followed households over 10 years and were able to show that there was an increase in the percentage of households with orphaned children and an increase in the percentage of female headed households. This study compared demographic surveys from 2003 to the same surveys completed in 1997 and 1992. The period of 1997 to 2003, being a period when HIV prevalence was extremely high in this area. Female headed households and households with orphaned children would be expected to face much greater challenges than families with more productive members and fewer dependant members.

In a household level study, again in South Africa, Bachman and Booysen (2006) attempted to disentangle cause and effect in the poverty and HIV association. This study found that homes affected by HIV showed a 34% reduction in monthly spending when affected by an AIDS illness and a 23% reduction in monthly spending when affected by an AIDS death. This study demonstrated that AIDS suffering does in fact cause an increase in poverty for all those surrounding the patient.

2.3 Setting

When considering any individual's HIV narrative, it is essential to first situate it within its economic context, which is often one of poverty (Russell et al., 2007). This is true for several reasons; first, poverty is important because individuals affected by poverty are more vulnerable to HIV infection (Remien & Mellins, 2007). Secondly, poverty is important because HIV is economically devastating for those infected as well as their entire households (Hosegood et al., 2007). What worsens this interaction of poverty and HIV is that HIV is sexually transmitted. HIV tends to cluster in families (Barnett & Whiteside, 2002) and the economic impact of these repeated incidences of illness is cumulative, often leaving families ruined (Hosegood et al., 2007). Placing the narratives of this study in context requires describing their economic context. Poverty is a dominant feature in the lives of residents of rural Western Uganda, which is the region in Uganda containing Rwimi Sub-county.

Western Uganda is one of the least urbanized regions of Uganda with only five percent of individuals residing in cities (Ministry of Health and ORC Macro, 2007). In 2003, UNSTATS estimated that in Uganda as a whole, 41.7% of the rural population lives on less than a dollar a day. It can therefore be assumed that the income of close to half of the respondents of this study fell at or below this important cut off. In Western Uganda, approximately 60% of the working population said that they depended on subsistence farming as a major source of earnings (Uganda Bureau of Statistics, 2006). HIV infection is especially economically devastating to families who rely on subsistence faming because physical labour is their most important asset (Russell et al., 2007).

When an HIV infected individual becomes symptomatic, the family becomes doubly disadvantaged. The patient is unable to work due to illness and the caregiver is unable to work because of the time demands of caring for the patient. As subsistence famers do not earn wages, cash which is required for illness related costs must be raised by the selling off of assets (Barnett & Whiteside, 2002, p 233).

Barnett and Whiteside (2002, p 193) have argued that as greater numbers of families are affected by HIV in a given area, entire social networks are weakened as fewer and fewer households have any extra capacity to spare to help their friends and neighbours. This means that HIV prevalence rates are another important piece of contextual information. HIV has been present in Uganda since the early 1980's and the most recent estimate of prevalence rates for Western Uganda, are 7.8% in women and 5.7% in men (Ministry of Health and ORC Macro, 2006). Another important contextual factor is HIV stigma. In a 2006 survey, only 26.4 % of Western Ugandan respondents answered favorably to all four questions assessing acceptance of HIV infected individuals. This indicates that HIV stigma is still a significant issue in the area (Ministry of Health and ORC Macro, 2007).

Rwimi sub-County

Rwimi sub-County lies in the southwest corner of the Kabarole District, which is in the region of Western Uganda. There are limited descriptive statistics available which are specific to Rwimi sub-County. According to a 2002 census, the population of Rwimi is thought to be 24, 999. The average household size is 4.6 people (Uganda Communications Commission, 2003). A survey done by a local university student, found that the predominant faith in Rwimi is Christian, with Catholic and Anglican being the most common Christian religions. Approximately 10% of the population is Muslim. This same survey found that over half of the population has a primary level education or less and that the main tribal associations in Rwimi are with the Batooro, Bakiga and Bakonzo tribes (Rubaihayo, 2007).

The population density for Kabarole as a whole is 215 persons per kilometer squared. The total fertility rate in Kabarole is also very high at seven. This results in a very young population (Uganda Communications Commission, 2003). These statistics can be assumed to also hold true for Rwimi sub-County.

CHAPTER 3: OBJECTIVES

3.1 Purpose of Study

The Antiretroviral Rollout is a massive undertaking with the potential to change the face of the HIV epidemic in Africa. At present there is inadequate knowledge of the outcomes of this intervention. The purpose of this study was to gain an increased understanding of the impact of HAART on both the patient receiving this treatment and the primary caregiver of these patients. Inquiry will be focused on emotional wellbeing and social relationships. However a limited discussion of physical wellbeing will be included in order to segue to the more sensitive focus of the interview guide.

The information gained from this study will add to a body of knowledge that will enable those affected by HAART to be better understood and supported by health and social service agencies.

3.2 Research Questions

1) What is the impact of HAART on the physical and emotional wellbeing of both the patient and his/her primary caregiver?
2) What is the impact of HAART on the social relationships of both the patient and his or her primary caregiver?
3) Are there any problems or concerns that have arisen for the patient or the caregiver as a result of the patient taking HAART?
4) What has been the impact of HAART on the perceptions of the future for both the patient and the primary caregiver?

3.3 Methodology

The methodological basis of this qualitative study is constructivist grounded theory as described by Charmaz in her articles (2000; 2002) for the Handbook of Qualitative Research.

Qualitative methods were chosen for this study because the goal of this study was to gain an understanding of the complicated social and psychological changes which occur in the lives of patients and caregivers as a result of the patient taking

HAART. The main advantage of qualitative methods over quantitative methods (for the purposes of this study) is that qualitative research prioritizes preserving and describing the complexity of the participants' lived experience. In qualitative methods there is a focus on remaining true to the often messy details of the phenomena in question (MacDonald & Schreiber, 2001, p 36).

From the array of qualitative methods available, grounded theory was chosen as a basis for the design of this study. Grounded theory methodology was originally developed in order to study "basic social or psychological processes" (Charmaz, 2002, p 677). In this study, the "basic process" in question is the changes that patients and caregivers experience in their lives as they adapt to their new realities. The goal of grounded theory is to build understanding upward from the data which is collected rather than downward from any pre-existing theory (Streubert & Carpenter, 1999, p 102). In an effort to build upward from the data, grounded theory researchers are encouraged to analyze and collect data concurrently and allow the incoming data to guide sampling and data collection decision making.

The concurrent data analysis and data collection that is central to grounded theory allows for a flexibility in methods (Streubert & Carpenter, 1999, p 102) that is ideally suited for areas of study where there has been little previous research, as is the case for the focus of this study.

As originally conceived by Glaser and Strauss in 1967, grounded theory methods are very positivistic (MacDonald & Schreiber, 2001, p 38). Underlying these methods is the assumption that the researcher is an unbiased agent, who, if successful does not hamper the purpose of the study, which is to uncover the singular "truth" which explains the social or psychological processes in question.

Since grounded theory was initially developed, postmodernist ideas have become increasingly influential in qualitative research and researchers have reflected this evolution and turned away from the positivistic orientation of grounded theory (MacDonald & Schreiber, 2001 p 41). Researchers who adopt postmodernist ideas reject the notion that there is a single interpretation of human behaviour that can claim to represent the "truth". This is a fundamental, philosophical shift which accepts the possibility that there are can be multiple realities or explanatory theories, all of which have equal truth value. Postmodern researchers also reject the idea that a good researcher is unbiased and does not influence the research process (Cheek, 2000, p 35).

A constructivist interpretation of grounded theory builds upon postmodern ideas and acknowledges that the social reality that is presented as a result of the research process is "co-constructed" between the researcher and the participant. In constructivist grounded theory, it is acknowledged that the version of reality that is co-constructed is influenced by many factors which are particular to the researcher, the participant and the environment in which the research is taking place (Charmaz, 2002, p 677). These factors could also be thought of as being context for the results of the study. Put another way, constructivist grounded theory acknowledges that the context for the research influences the results of the research and attempts to incorporate these ideas into the study design.

The challenge presented to researchers who adopt postmodern ideas in their research is that their research is not valuable because if there can be multiple theories which all accurately explain a given reality, then the version of the social reality that they are trying to assert in their research is just as valuable as any other interpretation of this same social reality. Challengers of postmodern research feel that the acceptance of the veracity of multiple realities is also an acceptance of nihilism (MacDonald & Schreiber, 2001, p 50).

The philosophical writings of Lyotard and Longino attempt to answer this challenge in such a way that preserves the value of postmodern research. Longino (1990) proposes something that she calls "contextual empiricism", which has also been called a weak version of constructivism (Schwandt, 2000, p 198). Lyotard (79/84, as cited in Macdonald & Schreiber, 2001, p 40) suggests the adoption of the "little narrative". The "little narrative" is a way of describing human action that values and preserves the details of individual experiences. This is in opposition to the "grand narrative" which seeks to make sweeping generalizations about the entirety of human experience. Both of these philosophers state that social and scientific research can retain its value, which is offering an explanation of events which is more credible than other explanations by paying careful attention to the context in which the research was done. Longino (1990) states that the scientific community must continue to have faith in experiential evidence and allow this evidence to guide decision making. However she also states that the context for the collection of this evidence must be attended to in order to remain cognizant that a different context may produce different "evidence". Similarly Lyotard espouses that describing social experience has little meaning unless the time, place and person are also described in order to give a complete understanding of the individual in question (79/84 as cited in Macdonald & Schreiber, 2001, p 40).

The "contextual empiricism" or adoption of the "little narrative" described above is the philosophical stance which this research project adopts; that the results of this study are a credible interpretation of the process in question, however, these results are a product of the specific context within which they were developed. Therefore a great deal of effort will be taken to describe the context of the research results and to frequently discuss individual experience.

The only deviation from constructivist grounded theory methods taken by this study is that the end result of this study was not the development of theory, but of a complex description of the changes experienced by the participants after HAART. Grounded Theorists seek to develop a theory as the end product of their research (Streubert & Carpenter, 1999). The goal of this theory is to elevate the data from its context and produce a model which can predict and explain the behaviour of individuals within the basic social process in question in another setting (Schreiber, 2001, p 78). In this study there will be no attempt to lift the data from its context or provide a model with predictive or explanatory power. Some researchers in fact argue that the production of theory is at odds with the postmodernist ideal of remaining true to the complexities of the "little narrative" which must be subsumed in order to produce an overarching theory (Macdonald & Schreiber, 2001, p 48).

CHAPTER 4: METHODS

Data for the study was collected using semi-structured, individual and group interviews. All respondents who were interviewed individually were interviewed twice. Focus groups were conducted only once. Ultimately 54 individual interviews were completed with patients and caregivers from 14 households and four focus groups were conducted. All interviews were completed by Research Assistants in the local languages of Rutooro and Rukiga. Interviews were then translated into English and transcribed for the Primary Investigator.

The goals that the research team hoped to accomplish by interviewing all participants twice were several. Because the topics of the interview guide were very sensitive in nature, it was hoped that two interviews would give the respondents adequate time to describe their feelings and experiences around these complicated topics. It was also hoped that two interviews would allow a sense of trust and familiarity to develop between the respondent and the research assistant. This would allow a deeper insight to be elicited from the respondent. Frequently there were changes in the testimonies of the respondents as this sense of trust developed that was itself a useful observation.

The interviews were generally one week apart. The time lapse between the first and second interview had some benefits to the data collection process. This time lapse allowed the research team time to understand and explore the responses offered in the first interview, which allowed for a significant development of the interview guide for the second interview. It also happened on at least two occasions that there were significant events in the lives of the respondents which occurred in the week between interviews that helped to emphasize a certain aspect of respondent's post-HAART reality that may have otherwise been overlooked.

4.1 Individual Interviews

Sampling

Patients were selected from the records of the CB-ARV Project. Therefore the possible population for this study has conformed to the inclusion and exclusion criteria for the CB-ARV Project. A selected list of criteria includes; the patient is 18 or older, could not afford to purchase HAART on his or her own, lives in the geographic zone of the study and has a stable home. The patients must also have met the WHO criteria for AIDS in stages three or four (Community Based, 2005 b). Individuals in these stages are very sick, often showing severe weight loss, chronic diarrhoea, multiple opportunistic infections and some dementia (WHO, 2006, pg 88). The only additional criteria for this study was exclusion criteria which were two; persons unwilling or unable to provide informed consent for this study and caregivers under the age of 13 would not be selected for individual interviews.

As a theoretical sampling method was used, no sample size was determined during the planning stages of the study. However practical considerations necessitated that some thought be given to how to reach the point of data saturation during the time period allocated for data collection. As the sample size was planned to be small, effort was made to reduce some of the sources of variation in the respondents. In effect, the hope was to gain a better understanding of a more limited version of the phenomena in question.

Important sources of variation for the respondents were thought to be factors such as; age, sex, severity of patient's illness prior to commencing treatment, duration of treatment and degree of improvement achieved with treatment. Efforts were made to maintain diversity in demographic variables such as age and sex and reduce variation in treatment and illness experience of the patients.

All patients in the study had been on HAART for six to 12 months. An effort was made to keep the duration of HAART as close to nine months as possible, however there were not enough patients enrolled in the project during that time period. It is thought that the majority of physical changes in the patient's experience after commencing HAART are completed after three months of treatment (Booysen et al., 2007). Therefore the six to 12 month duration was chosen because all physical changes were likely to be completed, yet the respondents would likely still be able to remember some details of their situation before the start of treatment.

Severity of illness was assessed using the Functional Status which was recorded on the patients chart at the initial visit when starting HAART. This measure of illness severity was chosen as it was thought to be a better indicator of how sick the patient actually felt. It is often the case that clinical indicators, such as CD4 cell counts and HIV-1 RNA viral load are not congruent with the experience reported by the patient (Brashers et al., 1999). It was hoped that all patients who participated in the individual interviews would have a Functional Status rated as three at the start of treatment, which according to the Rwimi chart information indicated that a patient was bedridden for 50% of the day or more. However, there were not enough of these patients in the treatment duration described above and some patients who were Functional Status two had to also be included. A functional status of two indicated that the patient was still bedridden, but for 50% of the day or less.

Degree of recovery was more difficult to assess from the patient records as the design of the CB-ARV project is that after the initial six month check up, patients do not have to return to the Health Centre unless there is a concern. Therefore degree of recovery was assessed by reading the Physician/Clinical Officer notes in the charts at the first check ups. Also the fact that the patient had not been to visit the clinic recently was taken to mean that the patient was in good health. However it was recognized that lack of attendance at the clinic could be due to other factors.

The sampling of caregivers presented more challenges than the sampling of patients. The patient's clinic record contained information regarding the other members of the patient's household as well as the name and relationship of the patient's treatment partner. From this information, some "educated guesses" could be made regarding who was the patient's primary caregiver. However it was necessary to discuss with the patient at the first visit to the home, which family member provided the bulk of their care when they were acutely ill.

Saturation

It was hoped that saturation of the data could be obtained by interviewing 10 to 15 households. After the thirteenth household, the Primary Investigator and the Research Team felt comfortable that saturation had been reached. However, by that point, the arrangements had already been made to conduct the interviews with the fourteenth household. It was decided to proceed with these interviews. It was therefore not considered to be very detrimental to the study when the second set of interviews at the fourteenth household could not be completed due to an outbreak of infectious disease in the area, which was beyond the control of the Research Team.

Recruitment

The Volunteer Health Workers in the CB-ARV project were asked to assist the research team in recruiting the respondents in this study. This was done as the presence of researchers at a patient's home could alert the members of that person's community that he or she was infected with HIV. As the Volunteer routinely visited the home of the patient, no unwanted attention would be attracted to the home prior to the household members consenting to participate in the study.

Volunteers were contacted one to two weeks prior to the planned visit and again immediately before the visit to the patients home so that the volunteer could let the researchers know if it was acceptable to the patient to proceed. No patients declined to be interviewed. One patient chose to be interviewed at the Volunteer Health Worker's shop instead of her own home due to a conflict in her family. All respondents were given the option to meet with the research team somewhere other than their home, with all transportation costs reimbursed.

As mentioned above, all interviews but one took place in the homes of the respondents. Both patient and caregiver were interviewed on the same visit to the home, but separately. It was important, yet at times difficult to find a private place in the home to conduct the interviews. Often interviews took place outside of the house in a secluded area of the compound.

Two Research Assistants (RAs) went together to each visit to the home. One Research Assistant interviewed each respondent, but both RAs sat in on both interviews. At the end of each interview the RA conducting the interview gave an opportunity for the other to add any questions that were missed.

The same RA-respondent pairing was maintained for both the first and second interviews. An effort was made to have the one male RA interview the male patients and one of the two female RAs interview female patients though this was not always possible. All three Research Assistants felt it was appropriate to have men interviewing women and women interviewing men.

The Primary Investigator attended only the early interviews of the study. This was done in order to observe how the interviews were being conducted, give suggestions for change and ensure that informed consent process was being carried out properly. The presence of the Primary Investigator was minimized in order to limit the incidence of respondents overemphasizing their poverty in hopes of receiving gifts from the white researcher.

The interviews ranged in length from 20 to 90 minutes, depending on the openness of the respondent. Generally the interviews were one week apart and the appointment for the second interview was made at the conclusion of the first. Demographic information about the household was collected at the end of the second interview. The demographic data included age, occupation, religion, members of the household, RA's impression of education/literacy level, ownership of animals and means of transportation and communication.

Remuneration

Both respondents from each household were given small packages containing salt, soap and sugar to thank them for participating in the study. This was deemed appropriate as the respondents had to sacrifice two mornings of work in order to meet with the research team. For the early interviews, this package was given at the end of the second interview. This was then changed and given at the end of the first interview as the research team felt this was more appropriate.

4.2 Focus Groups

Sampling

Again as the study population were all participants of the CB-ARV project, there were few additional inclusion or exclusion criteria for the focus groups. If respondents had already participated in the individual interviews, they were not asked to attend the focus groups. Also caregivers under the age of 18 were not asked to participate in the focus groups.

On the whole, the sampling process was much less selective for the focus groups as compared with the individual interviews. Participants in the focus group interviews were quite diverse with respect to; treatment duration, illness severity and response to treatment.

It was hoped that a support group (known as a "post test club" in Uganda) that had formed amongst the patients of the CB-ARV project would agree to participate in a focus group for this study. It was recognized that the members of this group would likely be more advantaged in many ways than most patients of the CB-ARV project. In particular these members would likely be much more comfortable dealing with HIV stigma. It was decided to go ahead with the interview of this group as they were easily accessible and it was thought that the less advantaged patients of the project would be represented in the individual interviews.

Ultimately four focus group interviews were completed; one each with male patients, female patients, female caregivers and male caregivers. During the planning of this study it was thought that male caregivers would be too few in number and too inaccessible to make holding a focus group with them possible. However the primary investigator was encouraged otherwise by both the volunteers and the volunteer coordinator, so an interview with this group was also planned.

Recruitment

The primary investigator first approached the leader of the post test club to ask permission to attend a regularly scheduled meeting in order to introduce the study. This was agreed to by the leader of the post test club. At the meeting, all members of the post test club accepted to reconvene at a later date for a focus group discussion.

As the Post Test Club contained only two men, the male patient focus group was a mixture of men from the post test club and men from the community. For the male patient focus group and both of the caregiver focus groups, the Volunteer Health Workers were asked to recruit participants through word of mouth.

Getting appropriate numbers for the focus groups was difficult. The female patient focus group included 12 respondents. The male patient focus group included eight respondents. Both of the caregiver's focus groups contained only three individuals.

All focus groups were held at the Rwimi Health Centre on Fridays, which coincided with market day in the nearby trading centre. All focus groups were conducted in either Rutooro or Rukiga (these languages are similar enough to be comprehensible to speakers of either language) by one of the Research Assistants. Informed Consent was obtained from all individuals in the same method as the individual interviews prior to the start of the focus group session.

Remuneration

All participants in the focus group discussions were told prior to attending that they would be reimbursed the cost of their transport to the Health Centre. Snacks were also supplied.

4.3 Interview Content

First Interview

To ensure some consistency between interviews, an interview guide was prepared. The interview guide that was used for the individual interviews was used as a template for the focus groups, however the number of questions asked in the focus group sessions were much fewer than in the individual interviews. Research Assistants for all interviews were encouraged to use this interview guide only as a list of possible topics. RA's were encouraged to use as much unstructured talk as possible in the interviews. The importance of using probing questions and searching for deeper meanings was repeatedly emphasized.

Questions were added to the interview guide as important issues emerged during the data collection process. A collection of the interview guides used is contained in Appendix A. A selected list of topics for the interviews included; description of pre-HAART era, changes in socializing outside the home after HAART, changes in family relations after HAART, changes in levels of anxiety, depression, hopefulness, present thoughts about life expectancy, priorities for remaining time and concerns about health or medication.

Second Interview

In most cases, the prepared interview guide was completed at the first interview. It was originally thought that discussing all of the topics in the guide would take both interviews. In order to have a set of questions as a guide for the second interview, the primary investigator read the transcript of the first interview and prepared a new question guide for the second interview. Each interview guide for the second interview was unique. Very often the second interview was used to clarify issues that were not clear from the first interview, to delve deeper into personal beliefs and elicit more details about life events that would put present circumstances in context. This produced interviews that were much more focused on personal narratives than originally expected.

Though the need to prepare a second interview guide for the second interview was an unexpected event, it was fortuitous in many ways. It was an excellent way to give the primary investigator more control over the interview process when not physically at the interviews. It also allowed the interview process to be truer to the iterative nature of grounded theory methodology. Lastly it allowed the primary investigator an opportunity to more fully appreciate the importance of the events which led up to the patient testing for HIV and starting treatment.

All of the Research Assistants felt that the respondents were much more relaxed and open in the second interview. In many instances, the second interview produced a much different picture of the family situation than the first interview. This was also illustrative to the research questions of the study.

4.4 Research Assistant Training

In total four Research Assistants were used to interview patients. All Research Assistants were highly educated, very fluent in English and Rutooro and had experience conducting research. Two of the four Research Assistants had previously worked with Researchers from the University of Alberta and were trained in qualitative interviewing. These two Research Assistants carried out both individual interviews and focus groups. One Research Assistant carried out only the female focus groups. The last Research Assistant carried out only individual interviews.

Considerable time was spent with the Research Team discussing the interview guide and what was the essence of life experiences and beliefs that were being sought. The importance of probing questions was repeatedly stressed. Strategies for rapport building and dealing with reserved respondents were also discussed. After consideration by the Research Team, the interview guide was left in English and the RA's would read the guide in English during the interview and then speak to the respondent in Rutooro.

4.5 Data Recording

All interviews were recorded with two recorders using one as a back up. Interviews were then transferred to a computer file and finally onto a CD. One copy of the audio files is on the primary investigator's computer in Canada. The set of CDs containing the interviews is stored safely at the CB-ARV office in Fort Portal, Uganda. The quality of the recordings is generally very good. There were few minor instances of the recording being obscured by rain or participants sitting too far from the recorders. In total there was perhaps one paragraph of data lost in this way.

After each interview the Research Assistants prepared field notes. The field notes were to contain any information that would not be recorded on the transcript such as condition of the house, rapport between the Research Assistant and the respondent, non verbal communication and the interactions between the patient and the caregiver. The form which the Research Assistants completed to record these field notes is contained in Appendix B.

4.6 Transcription and Translation

All of the transcription was done by the two Research Assistants who conducted the interviews and had been previously trained in qualitative methods. There is not a great deal of detail present in the transcripts, as this was not thought to be possible or necessary. However periods of long silences and incidences of tearfulness are noted.

The Research Assistants listened to the interviews in Rutooro and then transcribed in English. All names were removed from the transcripts to protect confidentiality.

Verification of Transcripts

Transcripts were verified in several ways. Firstly, one interview was transcribed by both of the Research Assistants and the final versions compared. Transcripts were also "spot checked" by the primary investigator by listening to the recording of the interview while sitting beside the third member of the research team. The Research Assistant would verbally translate what was heard on the recording and the primary investigator would compare that to the written copy of the transcript.

Inappropriate summarizing and inconsistencies were discovered in the transcripts and finally a person external to the research team was hired to review all of the transcripts and correct any errors.

4.7 Rigor

As the methodological basis for this study incorporates several postmodern philosophical ideas, verification of research outcomes necessarily becomes a confusing issue. Verification has become a much debated issue amongst researchers who accept a postmodern premise for their research.

When researchers seek to verify the results of their study, the hope is that they can claim their research results to be both valid and reliable. Validity being an accurate representation of the (singular) truth, and reliability being the ability to be reproduced in another context (Silverman, 2005, p 210). Research which is based on constructivist ideas does not attempt to assert that these research results could be reproduced in another place and time, with different individuals. Nor does it claim to be the only true interpretation of the data which has been collected. However there is still a need for researchers to give the readers of postmodern research a reason to have faith in the interpretation presented in the study as opposed to any other interpretation (MacDonald & Schreiber, 2001, p 47).

Given these challenges, constructivist researchers can still claim that their results have been verified through appropriate theoretical sampling which, if done well will result in an adequate saturation of the emergent concepts (Morse, Barret , Mayan, Olson & Spiers, 2002). The ways in which appropriate sampling was done with regard to this study will be outlined in the following section.

In grounded theory methods, verification is ensured by building two very important ideas into the sampling process. Firstly, the researcher's emerging ideas about the social process in question must be confirmed with further data collection, therefore the sample must be of adequate size to have confirmed all of the emergent concepts. Secondly, the sample must be diverse enough to ensure that these developing ideas are not based on only one particular type of respondent, which would artificially influence the researcher's ideas (Morse & Field, 1995).

The single most important verification step taken in this study was the second interview that was conducted with all but two of the respondents of the individual interviews. The second interview allowed the research team to follow up with the same respondent to ensure that that respondent's comments had been interpreted correctly. It also allowed the research team to gather more of the respondent's life story with which would allow for a fuller understanding of key events. The second interview was an invaluable way to confirm the new ideas which were developed from each and every participant and undoubtedly lead to a more complete understanding of the phenomena in question.

Adequate sampling in the study was ensured in two ways. The sample for this study was both large (at 54 individual interviews and four focus groups) and diverse.

Ensuring that the "proper amount" of diversity was present in the sample was an issue that required constant attention at every stage in the study. It was important that sufficient diversity be present to be able to saturate the concepts fully, however excessive diversity in the sample would have posed practical problems as the time period for data collection in this study was finite. A further challenge to achieving this important balance was that the charts upon which the primary investigator had to rely for information did not contain all of the needed information and occasionally were incomplete or inaccurate. This was especially a problem with respect to caregivers as there was virtually no information about them in the patients' chart. This chart information had to be relied upon as it was not feasible to "pre-interview" patients and caregivers to determine if they met the desired selection criteria.

Not surprisingly, this ultimately resulted in a sample which was more diverse than was originally intended. This wound up being an asset to the patient data set and a challenge in the caregiver data set.

There were two patients selected for the study who served as "negative cases" because their experiences brought to light issues that may have otherwise been missed. One patient had not recovered well after HAART. The other patient claimed that before she started on HAART, she was only bedridden for a very brief period and did not have any visible symptoms of HIV that would alert others in the community to the fact that she was HIV positive. Both of these patients were able to discuss these variations in their illness experience in such a way as to help bring the research team's attention to the importance of these issues.

Several themes which emerged from this study have also been documented in the scholarly literature. This lends credibility to the veracity of these themes.

Adequate saturation of emergent concepts is another important factor which must be considered when examining the rigor of a qualitative study. Being able to compare the interviews of patients and caregivers to each another was an asset to ensuring adequate saturation of concepts in this study. While it was never the intention of this study to examine objective truth by comparing patient and caregiver interviews, the fact that there was consistency between patients and caregivers on several key themes was valuable. The key themes on which there was agreement are discussed at the start of the Caregivers Results section. By hearing agreement between patients and caregivers on these important issues, it allowed the investigators to validate their interpretation of these themes and confirm that they were beliefs held in common amongst those most affected by HIV and HAART.

Documentation of data collection and data analysis processes is also essential for verification, so that other researchers can assess the quality of these processes. The interview guides and lists of codes which are contained in Appendices A and C respectively allow these processes to be audited.

Conducting Cross Cultural Research

It has been suggested by many scholars (Im, Page, Lin, Tsai & Cheng, 2004; Mill & Ogilvie, 2003) that there are additional criteria which need to be attended to in order to ensure quality when conducting cross cultural research. Im et al. (2004) suggests that it is essential to attend to issues of culture when conducting research because culture provides context that is essential to understanding the data. This is very much in keeping with the philosophical premise for the study stated earlier.

Im et al. (2004) have suggested that cross cultural rigor can be ensured when researchers follow five criteria which include cultural relevance, contextuality, appropriateness, mutual respect and flexibility. Mill and Ogilvie (2003) have espoused similar criteria and added that their approach to ensuring rigor is based upon attention to cultural relevance in the planning stages of the study as well as allowing flexibility to make needed adjustments in order to respond to the conditions in the field. The primary investigator attempted to follow the above criteria by seeking input from those more familiar with Ugandan culture at all stages of the study from conception to data analysis. Methods were also left open enough that necessary refinements could be made to suit conditions in Rwimi.

The cultural relevance of the study topic and design was ensured by discussing ideas with faculty from the University of Alberta (personal communications, Dr Walter Kipp, Dr. Amy Kaler, Dr. Irene Shakar and Arif Alibhai) and Makerere University (personal communication, Dr. Sheba Gitta) in Uganda who had all conducted research in this setting. This project also built upon research that had previously been done in Rwimi sub-county by University of Alberta researchers. Feedback was sought regarding the relevance of the initial question guide from members of the CB-ARV staff, Peter Rwakilembe and Tom Rubaale and from the research team. The interview guide also evolved according to the emerging data, if a question did not seem to be relevant to respondents, it was eliminated from the interview guide and/or data analysis.

To ensure cultural relevance, it is also essential that the topic of the study can be said to be of some benefit or interest to the community itself (Im et al., 2004). The increasing accessibility of HAART has been an extremely important event in all of sub-Saharan Africa and Rwimi sub-County is no exception. Western researchers have very limited knowledge of the full ramifications of this intervention. It is unfortunately the case that a great deal of African HAART patients owe the availability of their free treatment to Western funding and aid schemes, it is therefore of relevance to the community that western researchers appreciate the full impact of this medication to patients and their communities.

Contextuality occurs when the researcher ensures that the data is interpreted within its proper cultural context (Im et al., 2004). To ensure a correct cultural interpretation of the interviews, the primary investigator relied heavily on regular debriefing sessions with the research team, as well as input from Peter Rwakilembe, the Volunteer Coordinator for the CB-ARV project, and Sylvester Kisembo, the Clinical Officer at the Rwimi Clinic. The three research assistants hired to work on the project were especially important. Mill and Ogilvie (2003) stated that during their research in Ghana, their research assistants played a much more collaborative role than is usually the case for research assistants. This was also true with this study. The primary investigator's collaboration with the rest of the research team was invaluable to the evolution of the study and proper analysis of the data.

A frequent topic of conversation at the meetings of the research team was how to communicate with respondents in such a way that would build trust and respect. The primary investigator encouraged the research assistants to treat the respondents as experts and to ask the respondents for their assistance in gaining an understanding of their life experiences. Adjustments were constantly being made to the research process to ensure that methods were appropriate for the setting. One change that was made early in the interviewing process was that the primary investigator stopped attending interview sessions. This increased the cultural appropriateness of the interview by removing some of the attention that was generated when a white researcher visited the respondent's home. The research assistants noticed that respondents were dramatically more at ease when the primary investigator was not present.

4.8 Ethics

Ethical Approval for this study was obtained from the Health Research Ethics Board Panel B at the University of Alberta before leaving for Uganda. Upon arrival in the country an application for Ethics Approval was requested from the Uganda National Council for Science and Technology, which was granted. Copies of both Ethics Approval Letters are contained in Appendix D

As discussed in previous sections, interviewing patients in privacy and use of the Volunteer Health Worker to introduce the study were measures taken to ensure privacy. Confidentiality has been maintained through secure storage of records and removing identifying information from the transcripts.

Informed Consent was obtained prior to the first interview with the respondents. A copy of the information letter which was translated into Rutooro was given to the respondent and the information letter was also read out loud. Reading the letter and consent form aloud ensured that the participant was informed about the study in spite of potential illiteracy. The respondent was asked to either sign the consent form or mark it with a thumbprint if they could not write. Copies of the consent forms were also left with the respondents, regardless of their level of literacy.

When children were interviewed, the informed consent process was altered. Children were read a simplified version of the information letter and asked to provide assent to participate. The parents of these children were also read an information letter pertaining to their child and asked to provide the official consent for their child.

It was essential for both ethical and data quality issues that all respondents in the study understand the confidentiality of their responses. It was very important that respondents understood that there was nothing they could do with respect to this study that would affect their medication supply in any way. It was stated in the information letter that non-participation and making negative comments about the drugs or the CB-ARV project would not alter the supply of free medication to the patient. It was similarly important that the caregiver understand that nothing that she or he said would be repeated back to the patient. These points were restated a second time for emphasis by the Research Assistants after reading the information letter.

Volunteers were also cautioned not to coerce anyone to participate in the study.

Information letters and consent forms are contained in Appendices E and F respectively.

4.9 Data Analysis

True to the grounded theory methodology, all interviews were read and analyzed as soon as they were transcribed. Often, all four members of the research team would meet to discuss emergent concepts. These meetings would help the primary investigator to understand the cultural context of the interviews as well as help the research assistants to understand the ideas of the primary investigator. Interview guides evolved throughout the data collection process as a result of these emergent ideas. Many memos were written in this time that helped to develop ideas about data analysis.

Formal data analysis was done by the primary investigator upon return to Canada. The data analysis progressed through the stages of open coding, selective coding and axial coding, (Charmaz, 2000). Open coding is done by going through the transcript and naming the topic of discussion for each data segment. Data segments varied in length from a few words to one page depending on the complexity of the comments. Each one of the codes assigned during the open coding process had both a topical component and temporal component. The temporal component placed the comment in the respondent's personal story (for example during illness, at the time of testing, during recovery, present, etc). Interviews for both patients and caregivers were analyzed separately. At the end of the open coding process there were 113 codes for the patient interviews and 115 codes for the caregiver interviews.

Selective coding is the process by which open codes, containing smaller amounts of data are combined into larger groupings. Not all of the open codes were combined into larger codes and not all of the larger codes were included in the final analysis. The codes that emerge as primary are due to both the amount of discussion on that topic and the importance of these comments to the research questions.

Finally Axial Coding is the process by which the larger codes are combined and their relationships to one another are examined.

A great deal of free writing, also known as 'memoing' was done by the primary investigator as a way of developing and refining ideas on the emerging analysis.

All analysis was done using Nvivo software, version 8.

Lists containing all open and selective codes are in Appendix C.

CHAPTER 5: RESULTS

The Results Section will be divided into Patient and Caregiver subsections and will be discussed separately. Patient and Caregiver results are compared very rarely. This was avoided because the purpose of the study was to understand the respondents' own narrative and beliefs rather than find an objective version of the truth or analyze differences in the narratives. Both the Patient and Caregiver subsections will be further divided into appropriate topics. Two very important topics which are common to both Patient and Caregiver sections are the Context for Changes topic and the Changes after HAART topic.

As the research process progressed, it became more and more obvious that the thoughts and feelings expressed by the patients at the time of the interview could not be fully understood unless they were placed in the context of that person's previous life events. Put differently, it was found that the changes after HAART, which were meant to be the focus of this study, could not be understood unless that person's pre-HAART reality was also understood. Therefore gaining more information about the respondents' personal history became an increasingly important focus of the interviews. In order to better capture the description of the pre-HAART and post-HAART era's the Results section has been divided along those lines for both patient and caregiver. The pre-HAART description is meant to provide the context, which will help to better understand the post-HAART changes.

As the data collection progressed it was found that all patients went through several distinct phases during their illness and eventual recovery. These distinct phases were separated by hallmark events. While the amount of time spent in each phase and importance of these hallmark events varies from person to person, the general trend was common to all. Because of the diversity in the caregiver sample, no similar chronological pathway can be made for them, however general themes are discussed.

5.1 Patients

Description of Respondents

Table 1. Description of Patient Respondents

Age	<20- 1 20-40- 12 >60- 1		Marital Status	Single- 2 Married-4 Widowed-4 Separated-4
Religion	Christian-13 Muslim-1		Living Arrangement	With Spouse and Children-4 With Parents Only-1 With Parents and Children- 2 Alone-2 With Children Only- 5
Sex	Female-8 Male- 6		Education	None-1 Some Primary-13

There was a great deal of variety with respect to the patient's marital status and living situations. Four of the respondents had lost their spouses to HIV. Four respondents were married and living with their spouse. Two male respondents had never married and four female respondents were separated from their husbands. All but three of the respondents had children. Five of the patients had returned to live with their parents when they became ill and three of them remained after their recovery (all but one of these patients also brought their children with them). Five patients lived alone with their children. Two patients lived alone.

Only two patients were economically independent. Most participated in the economic activity of their family to the level that their health would allow. All families were involved in subsistence agriculture with varying levels of cash generating activities. These cash generating activities ranged from selling excess crops and other food products to operating a small shop. Levels of wealth amongst patients ranged from two men who owned their own land and also had small businesses to one woman who had been driven out of her home by her family. This woman had no possessions, was staying in someone else's empty house and when she was healthy would labour in other people's fields in exchange for food or money.

Context for HAART Changes

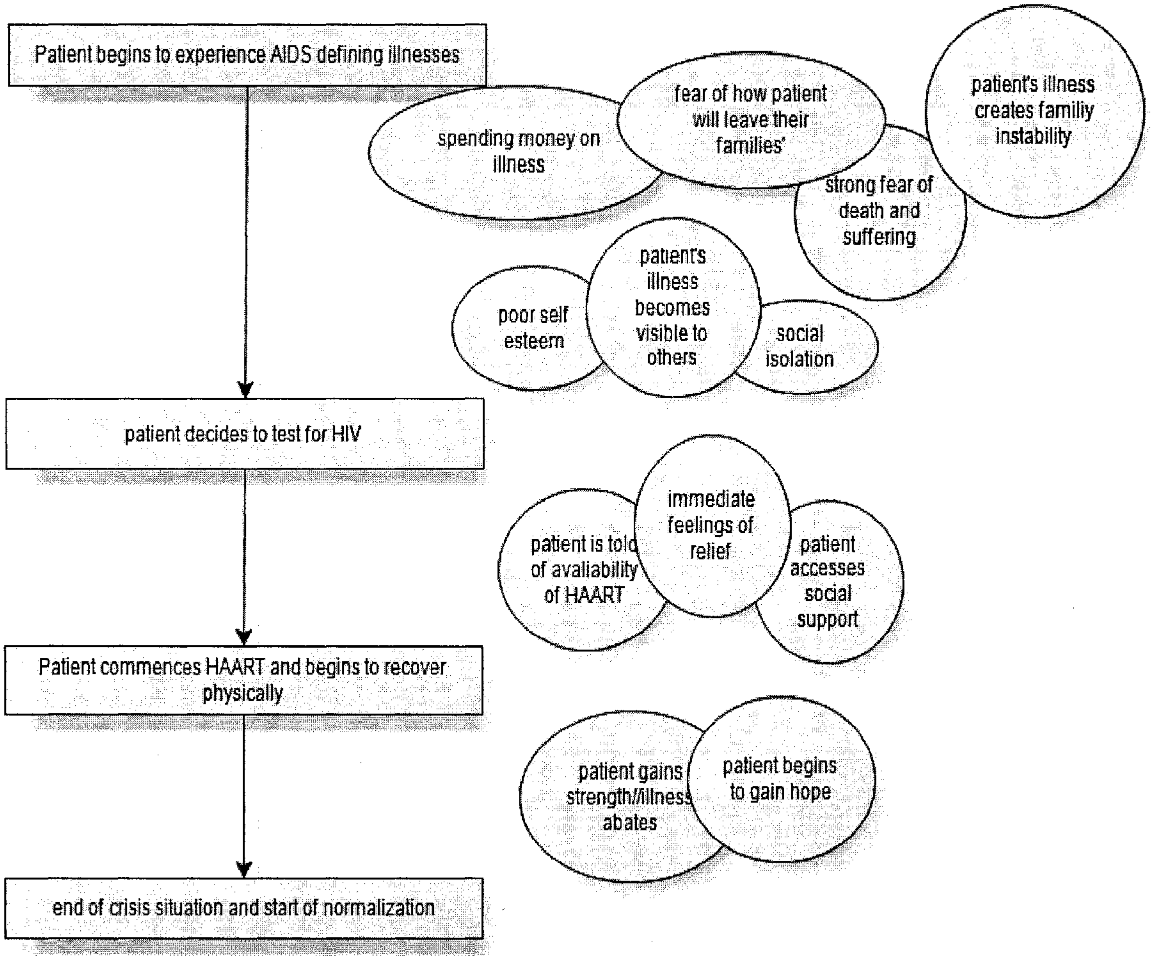

Figure 1. Chronological Context for Patient Changes after HAART

Illness/ Suspicion of HIV. All respondents spoke of the symptoms of AIDS as though they were common knowledge to all members of the community. Perhaps this is due to high prevalence rates or the fact that the HIV epidemic has been in the community over 20 years. One respondent spoke of learning the symptoms in school.

Patients' usually began their stories by describing the illnesses that they were suffering before they tested for HIV. The list of symptoms was long but commonly included fevers that would come and go, skin rashes, cough, weight loss and diarrhoea. As these illnesses increased in severity, people became increasingly suspicious that they might be infected with HIV.

> I started getting fever, then I would treat it with panadol then it could go today, tomorrow I go back to bed because of fever. Then I started losing weight very fast, then I thought to myself… "don't I have slim?"
> (patient 4, interview 1)

Some patients describe that it was not so much their own illness that made them suspect HIV, but the illness of a sexual partner.

> me,… I was sure I was sick because we got sick at the same time, me and the husband. I used to see people suffering from silimu *(HIV)* and what they talked about them *(was)* the way he *(my husband)* died, he was completely wasted.
> (Respondent from women's focus groups)

Significant events prior to testing. As the patients' physical illness progressed, the impact of their illness began to be felt in their social, financial and emotional lives. The period of acute illness was often described as a time of crisis by the patient. It was a time when family and personal coping mechanisms were taxed to their limit. The impact of the events which happened during the time of illness had far reaching ramifications which directly affected the post-HAART reality experienced by patients.

One very real impact which endured after the patient had started HAART was the financial consequences of the patient's of illness. It was a serious challenge for families to raise money needed to pay the transport fees needed to take the patient to the hospital as well as buy the needed medication. As few families had any means by which to generate cash, they were forced to sell possessions and borrow money. Friends and family were asked for loans, and domestic animals, plots of land and other valuables were sold off. Many patients described that they felt a great deal of distress over financial matters at the time, having to constantly worry about daily subsistence as well as finding extra money to treat their illnesses. The need to find money for transport and medication often happened repeatedly because many of the patients described falling ill, recovering, and falling ill again.

The following quote is from a married woman who tested positive along with her husband.

> Yes, when we were sick, before we got tested we found financial problems because we could go to hospitals and we would treat fever—we did not know what we were treating and we would spend money and the person would remain sick..........We sold goats, because at that time, we did not have money and the sickness was too much.
> (patient 13 interview 1)
>
> but before I tested , I wasted all my money on drugs for malaria, cough, headache.
> (respondent women's patient focus group)

Changes in the patients' physical appearance were also described as another significant event with broad ramifications in the emotional and social realms of their lives. All but one of the patients in the study described experiencing some degree of weight loss, skin problems or coughing that would be visible to other people. As the symptoms of AIDS appear to be commonly known in the community, patients became aware that others had begun to suspect that they had HIV.

> The neighbors used to see me, they knew it.
> (respondent women's patient focus group)
>
> Most people saw me, they know what I have been through.
> (patient 5 interview 1)

Patients reported feeling low self esteem as a result of looking bad and avoided going out to be around people as a result. People described isolating themselves because they were ashamed of what they looked like or were afraid people would not want to be around them for fear of catching their illness. For many patients, socializing was reduced simply because they were too sick to leave the house.

> had you seen me then I was no longer a person, I looked bad, I even feared being in people, I never wished someone to see me because all my body had changed. I was all wasted
> (patient 14 interview 1)

> Yes, my social life was disturbed so much I would avoid going to mix with people because I would feel bad if they said move there or here, you are going to give us your cough or eehh,-- what are you doing with such people when you know you are sick. So I did not feel comfortable around people. This brought me loneliness and feelings of inferiority around people
> (patient 3 interview 2)

Patients commonly described community members as being divided into two groups; those who were sympathetic, and those who were mean spirited. Patients felt that once mean-spirited individuals learned of your illness, they would laugh and gossip about you with others. Some patients said that they felt angry at these people.

The prevailing gossip that patients reported hearing about themselves was that they were useless and a burden. Patients stated that people with HIV were considered useless by those in their community because they were "bound for the grave" and will only burden the people around them more as time progresses. HIV and death were described as being synonymous. Furthermore, patients with AIDS were known to die a particular kind of death. This was described in great detail by the patients. An HIV death is thought to be one where the patient suffers for a long time with such indignities as: weight loss, constant diarrhoea and smelling of feces. Often the worst fear of this "bad death" is that the patient will die alone, having overburdened his or her caregivers.

> Dying badly is when you die, you die, there's no one around you because maybe you have bad smell or people have gotten tired of you. You die alone no one cares. Other people died with their mouth open calling for help
> (caregiver 10 interview 1)

During their illness, patients truly believed that this was what was in store for them. Very many patients reported that they had seen family or friends die of HIV and this memory made them very afraid for their own future. This fear of abandonment and prolonged suffering are very strong in patients. Patients said that the thought of death was always on their minds. They did not bother to think into the future as they did not think that they would live long.

> I saw them, people died diarrhoearating (*having diarrhoea*), passing out pus, sometimes even intestines came out and they would stink and other people would not

> want to be around them because of this bad smell ...... and the people who visited you would not stay for long—they would run away...... I thought about it and even thought about killing myself but again I feared.
> (patient 10, interview 1)

> because me I had lost hope and all my people and my friends had lost hope in me knowing I am dead. Because the point I was on was not for the living but for the dead.
> (respondent women's patient focus group)

Believing that their deaths were inevitable, patients started to worry about how they would leave their families. It is one of the hallmarks of the HIV epidemic to kill people in middle age, when they are in the midst of rearing their families (Barnett & Whiteside, 2002, p 161). Many of these patients had young children who were unable to care for themselves and had not yet completed their education. Not only had parents not saved enough to leave their families with a secure place to live or money for school fees, they were often leaving their families in debt because of their illness. This stressed patients a great deal.

> I used to think and worry about my child, I thought where was I going to leave my child she has not yet started school, still very young and eh.. eh.. eh.
> (patient 11, interview 1)

> thoughts alone wanted to kill me because I would look at my children, their father had died and left them with me. I had no one to leave them with if I died.
> (patient 14, interview 1)

When telling their stories, it became apparent that during their illness, patients often had to move from house to house in order to find adequate care for themselves. Some people reported a great deal of instability in their living situations. Many of the patients' initial care giving situations were not sustainable as their illness progressed. Patients described going through several caregivers, often having to physically move house in the process. This instability created even more stress at a time when patients were already feeling very scared and vulnerable. Many single patients had to move back home with their parents. Most of the patient's families were barely meeting their own needs both financially and in terms of workload. The addition of a sick patient was not a demand which was easily absorbed. Patients seemed to be well aware of the fact that the burden of their illness could easily overwhelm their caregivers. Many patients articulated that during their illness they experienced real fear that their caregivers would abandon them.

This fear was not unsubstantiated. Five of the fourteen patients in the study were either abandoned by their caregivers or so seriously neglected that they chose to leave and live elsewhere. Caregivers also corroborated that abandonment was a real threat. When caregivers were interviewed, many admitted that there was a time that they had considered leaving their patients.

As would not be unexpected in a situation of family instability and crisis, patients also reported that there was a great deal of conflict in their families. Even in the care giving situations that would seem from the outside to be more stable; the social and financial stresses introduced by a sick patient created tension in many families. Many patients felt that they had been neglected by their caregivers and this provoked arguments and feelings of pain and anger. Several women were left by their husbands when it became obvious that they were infected with HIV.

> I: Why would *(your mother)* mind to take you to the hospital, why?
>
> R: They were saying now if she has silimu *(HIV)*, why should they bother themselves taking her for treatment when she is meant to die, maybe she thought that she was going to waste her money on someone who is about to die.
>
> I: Now how did this behaviour of your mother towards you make you feel?
>
> R: I felt grieved and depressed and could not talk.
> (patient 5, interview 2)

Testing and accepting treatment. For all of the patients in the study, there came a point in time where the suspicion of HIV was too much and they decided to go for HIV testing. The reasons patients gave for deciding to test were varied and personal. For many women it was because their husband had recently died or tested positive, which eliminated a barrier that had kept them from testing earlier. For others it was because a sympathetic person told them that there was help available at the clinic and encouraged them to test. Whatever the reason that the person ultimately gave for testing, this was not an action that people undertook lightly. Patients described that they needed a great deal of courage to overcome the fear of testing. They also spoke of many others in the community who cannot overcome their fear of testing and "choose to die in ignorance", rather than know their status. Ultimately all individuals in the study spoke of testing as a watershed event in their journey with HIV.

> So it is not easy, that is why some of the people who are like me you find them doing the unspeakable things – they are completely confused like mad mixed with ruthlessness. It takes you to sacrifice yourself and test.
> (patient 3, interview 1)

In the design stages of this study, the importance of talking about HIV testing was not anticipated and therefore not specifically included in the Interview Guide. However when asked about their experience with HAART, people continually returned to testing as a hugely important event. It was the turning point that brought the medication into their lives.

All but two of the patients in the study tested for the first time with the CB-ARV Project. Most patients described hearing the news that they were HIV+ at the same time as hearing that there was medication available to help them. Therefore the devastating news that they were HIV positive was mitigated somewhat by the news that the situation was not hopeless, there was action that could be taken to help the situation.

As was described earlier, most patients had some level of suspicion that they were HIV + even before testing, therefore the results of their testing did not take them by surprise, but was a kind of relief that acknowledged what they already suspected to be true. Before testing, many patients were certain that they were going to die. They had long since lost hope in their lives. After testing and hearing that they would be started on medication, many patients said that they had optimistic thoughts about their health for the first time.

> I: Why were you happy about the news to know that you are HIV positive?

> R: I wanted to know because I was worried what I was suffering from. So when I got to know, I got peace and I knew when I started medication I am going to be healed and that is how I feel right now—I feel the peace
> (patient 4, interview 1)

Not only was choosing to test an important event in terms of accessing help for their physical health. It was also an important event from a social perspective. Many patients described going to test as the first time that they realized they were not alone with HIV. As was described earlier, during their illness, patients faced a difficult and often hostile social environment. Upon coming to the clinic, patients said that they were able to find comfort and hope in the words of the HIV counsellors. Many patients reported feeling a great deal of fear upon initially hearing their results, but once they were counselled, they were able to accept the situation.

> Me, when I tested and found that I had HIV virus, let's say I first got scared—but afterwards they counselled us and told us not to fear, they are going to give us medicine, we are going to be fine. Then I stopped fearing.
> (patient 13 interview 1)

Some patients also stated that in going to the clinic for testing, they were able to meet fellow HAART patients. They were relieved to meet other patients who were doing well on HAART. Patients said that while at the clinic, stories were shared and newer patients could take encouragement from the patients who had been on drugs longer. Perhaps for many, this was the first time that they had encountered a supportive environment for those who are HIV+.

> I was relieved because there were other people who had started on drugs and they were doing well and looking healthy….. because there are some people I thought I would find dead but they are still alive and looking healthy, this gave me more hope that I would also not die very fast.
> (patient 10 interview1)

> when I was going to the clinic, I thought I was the only one but to find out some even got there before me and others came after me, we are very many and some will even tell of their stories.
> (patient 8 interview 1)

Recovery/Crisis resolution. As patients became comfortable taking their medication, their physical ailments reduced and they gained strength. Patients described this period as a kind of "in between time". There was no agreement on the duration of this phase; one patient described a dramatic improvement that happened to him overnight, while another patient felt that his recovery took almost a year.

During this period of recovery, many of the problems associated with illness remained. Most patients said they felt too sick to work, still isolated themselves socially and had to find money to make trips to the clinic. However, in an emotional sense, circumstances were totally different. Patients who had counted themselves as dead, found themselves improving. The certain link with death had been broken. Physically patients felt as though they had turned a corner. An important event that people talked about was regaining their appetite. It was also a relief for patients to have a reduction in fever, pain and diarrhoea. Patients described that their sense of hope grew stronger and stronger during this time.

> Yes, I felt inferior, but I could say even if people will not understand me, I will soon be okay and walk again among them
> (patient 3 interview 2)

Changes after HAART

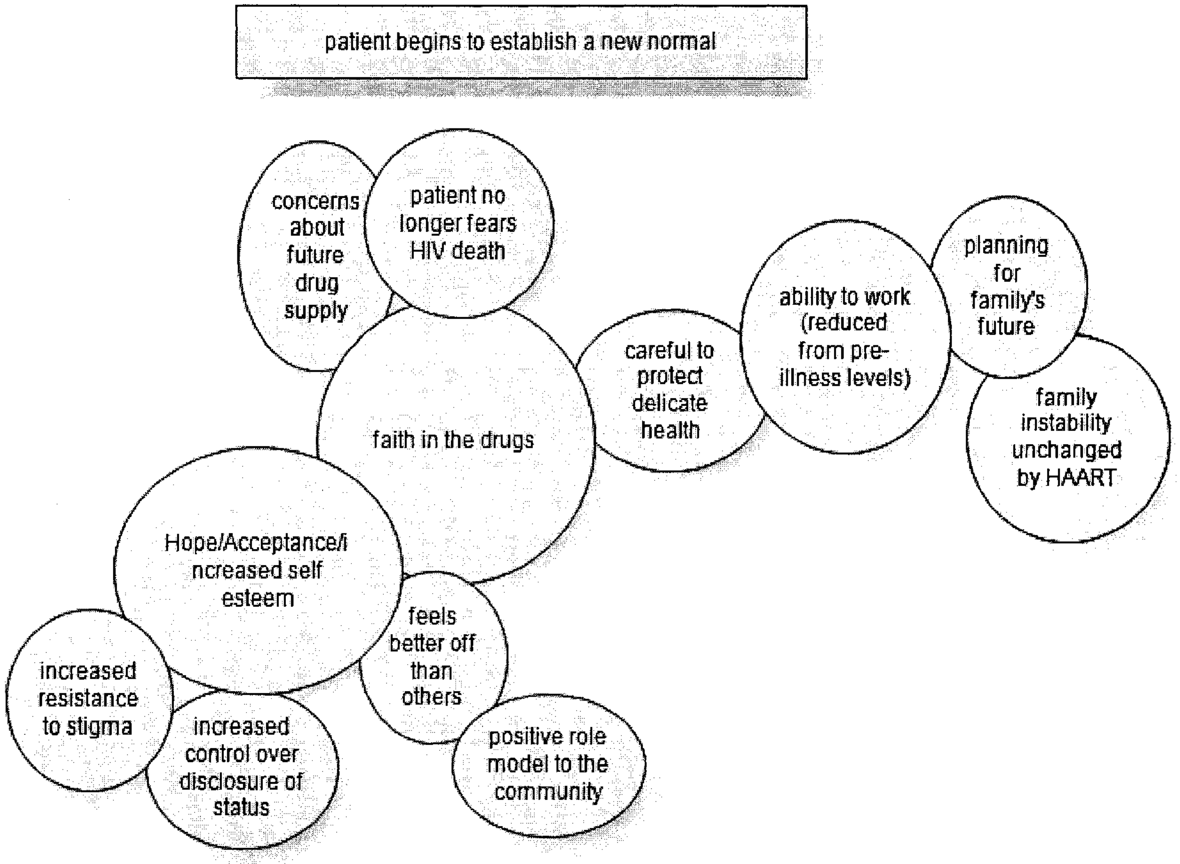

Figure 2. Patient Changes after HAART

As the patients' physical health began to stabilize, circumstances slowly became less dire for both themselves and their families. Slowly patients began to build their physical and emotional coping skills as the demands placed on them by illness reduced. Patients described a new sense of normal developing. There were still many difficult situations, but patients felt that they were able to manage their day to day affairs and most felt optimistic about the future. There are many beliefs and experiences common to all patients as they attempt to build upon this growing sense of normalcy.

Faith in the drugs. Patients spoke of the drugs with the utmost confidence, and with a regard that nears reverence. Several patients reported feeling some fear and uncertainty when they started on the drugs, but once they started to feel better, this fear quickly vanished. Patients described that they had been delivered from death's door by the power of these drugs and had a great deal of faith in them.

> Me, I feel it is the drugs that have given me the strength. Comparing how I was – I could not even wash my own clothes but nowadays – I can wash and do all the work I want to do. I think it is the drugs that have given me strength.
> (patient 1, interview 2)
>
> We even talk about where these drugs have got us from. We were almost about to enter into the grave but the medication has changed all that we thought about.
> (patient 8 interview 2)

In fact patients were so impressed by the power of these drugs that many expressed confident hope that one day they would be cured of HIV altogether. Several patients said they were sure that it would not be long before stronger drugs would come that can cure HIV completely. Several other patients made statements that indicated that they hoped they would be cured by continuing to take their drugs properly. All of the patients were well aware that they were not cured at the moment and had every intention of continuing with their medication, but some patients expressed hope that one day they would be able to stop because they would be cured all together.

> I am thinking, I know that now that there has come this medication to reduce on the disease, there will come also the medicine to cure us.
> (patient 13 interview 1)
>
> I know if I was peaceful I would get cured but I wouldn't stop the drugs because they told us that we take them all our life. But as I see myself, I think at one time I will get cured.
> (patient 10 interview 2)

Adherence was something that was taken extremely seriously by all of the patients. Patients knew that they must take their medication on time, twice a day. Many patients reported that once they set their minds to the importance of doing this, it was not a difficult task. Patients felt that adherence was important because the drugs were so powerful. They feared if the drugs were taken improperly, the power of the drugs could harm or even kill them. Patients felt that the level of health they had attained was entirely due to the drugs and without them they would likely die.

> I have no problem with it *(my drug regimen)*, I was given the time when to take and my drugs have caused me no harm, now I am used to them and they are part of me- they are like my food—it's about my life.
> (patient 8 interview 1)
>
> Me, I think if I stop taking drugs or even to just finish one day without taking them, it can be very bad for me, I can even die. Because they told us that we will take these drugs the rest of our lives.
> (patient 13 interview 1)

Concerns about the drug supply. When one considers the fact that patients' believe their health is entirely reliant on the medication, their concern about the supply of these drugs is easily explained. Many patients described living in fear that the supply of this medication will stop. Patients postulated that if they were to stop taking the drugs they would surely die. If there were drugs available for purchase, this would not help them because they could never afford to pay for the medication. Many patients mentioned that this was an area of great uncertainty and vulnerability in their lives and was entirely beyond their control. When many patients spoke about the drug supply, they stated that the drugs were being supplied by the generosity of the government or the "whites" and that this generosity was not reliable. Several patients said that there was no way that the government would be able to afford the cost of this medication, given the way that the numbers of sick people was increasing.

However not all patients were worried about discontinuation of the drug supply. Four patients stated that they had gained confidence in the medication supply due to the fact that until now their drugs had always arrived on time. All of the rest of the respondents in the individual interviews and focus groups expressed great fear that the medication supply could be interrupted.

> I think about it because you hear people say that the mzungu *(white)* will at one time stop caring for people and so I get that if they stopped I would die—I thought about that.
> (patient 8 interview 1)
>
> we know that if the drugs failed to be supplied that means death is automatic.
> (respondent women's focus group)
>
> I: You do not worry that the supply will stop?
>
> R: No—for that one, I have not worried about it--- because since they started they have never got short of them.
> (patient 13 interview 1)

All patients were asked if they worried that the medication could stop working for them. To a person, every respondent replied that they were not worried about this and continued to expound on their great faith in the efficacy of these drugs. While patients were not asked why they did not worry about viral resistance, it is assumed that patients were not taught about the possibility of developing personal resistance during their medication counselling. Therefore patients based their opinion of the drugs solely on their dramatic effectiveness to date.

Thoughts of death. Patients described having completely changed the way they thought about their own deaths because of the faith that they had gained in their medication. In the pre-HAART era, patients described the certainty and constancy with which they used to think of death. This is now gone. The weight of these thoughts was lifted and patients felt free think about their future.

> I: How do you see death far from you?
>
> R: It's now far away because now I go to bed to sleep with plans of what I will do the following morning but the other time I would sleep not knowing if morning will come.
> (patient 14 interview 1)

Not only were people relieved of thinking that they will die soon, they are also relieved of the fear that they will die one of the "bad deaths" associated with HIV. The common perception patients had of a death on drugs was completely different than the "bad death" suffered by AIDS patients. Patients said that they no longer feared the same kind of long suffering, undignified death. Now patients felt that when the time came for them to die, their deaths would be peaceful and quick. Several patients spoke of just dying in their sleep without any pain. Patients were confident that at worst, they would only suffer a very short illness, such as a brief bout of pneumonia or a very severe headache and then pass away. Many patients also expressed that they no longer believed that HIV will kill them, they felt they will die of another cause.

> And this thing of dying I have never thought of AIDS as the one which will kill me (patient 3 interview 2)
>
> I know I will just sleep without suffering and die.
> (patient 4 interview 1)

Dying this kind of death seemed important to patients for two reasons. Firstly, if they would just suffer a short illness and die quickly, there was no chance of overwhelming their caregivers. This saved patients from suffering the added pain of seeing their family overwhelmed to the point of rejecting them.

> But nowadays one just gets headache or fever for few days and pneumonia and one dies without disturbing anybody, you die when they *(your family)* still want to live or to be around.
> (patient 7 interview 1)
>
> They *(people on drugs)* get small sicknesses like fever and they die. Me, I would rather die like that than having diarrhoea on bed and have everyone first running away from me, avoiding me because I am smelling, because I am overworking them.
> (patient 8 interview 2)

There was a second point regarding death which was not made as strongly, but was alluded to by several patients. This was that dying a quick unpredictable death, when you have not had a chance to lose a great deal of weight, meant that people would not know that you had died of HIV. This was somehow a more anonymous death. Several patients said that they felt relieved that people in the community would not be able to continue gossiping about them after they had died. Avoiding the stigma associated with the stereotypical weight loss and shameful diarrhoea of AIDS seemed as important to patients after their deaths as it is in their lives.

> Yes- even now, people *(on drugs)* rarely die of HIV, they die of other diseases and accidents. People no longer die that way, they die peacefully, not the whole world to know ... I am not worried about how I will die- people will not make fun of me.
> (patient 10, interview 1)

Most patients were very reluctant to speak about how much longer they thought they would live. When asked this question most patients responded that they could not tell how much longer they had to live because this was ultimately up to God. Some patients stated that their life expectancy had returned to being unpredictable just like "normal people". The fact that patients were non-committal about their life expectancies, is itself a change from the pre-HAART era. During this time, when patients were sick with AIDS, they felt certain that they were going to die in the very near future. When patients were prodded to say how long they thought they would live now that they were on drugs, answers supplied ranged from 2 years to 50 years.

Finding hope. Feeling relieved about the conditions under which their lives will end is just one of the many emotional changes that patients described. When discussing the time when they were ill, patients spoke of emotions such as shame, fear, isolation and worry. Having experienced this recovery, patients more often used words such as peace, hope and strength. Though difficult problems still caused patients distress, this distress was not mixed with the hopelessness that seemed to prevail during the time when they were sick. Many patients described coming to a place of acceptance. While life was still very hard for many patients, at least now they felt progress was possible. Patients felt this way because they had a great deal more control over their circumstances than when they were ill.

> but when I got treatment and started medication. I got strong and settled and accepted the disease as it came.
> (patient 5 interview 1)

Ability to resume normal activities. One reason that allowed patients to find hope and dignity was the fact that patients could now "do their work". The importance that patients placed on the ability to work for themselves cannot be overstated. Patients returned to this subject time and time again. Economically, returning to work meant that patients could once again contribute to the family's finances, as opposed to being the devastating drain that they were when they were ill. However getting back enough strength to work was important in much more than an economic sense. In regaining the ability to work, patients described regaining dignity. They felt that they could again take some pride in their work and find value in their lives.

> I was very happy .. (Laughs) ....was very happy wondering if it was really me going back to the garden
> (respondent women's patient focus group)
>
> Yes, considering my past, the way I was too sick and now that I am back and can do my everyday work like any other normal person. That gives me hope to live, to plan.
> (patient 3 interview 2)

There was a great deal of disparity in the level of health that patients had attained at the time of interviewing. Some patients felt that they had the strength to resume their farming activities, though in a reduced fashion. However, about three patients could only do very light work, they definitely did not have the strength to go to the family plot and help with the crops ("go to the garden and dig"). However even these patients did something to generate income. All patients described being able to do basic household chores. Patients could now wash their own clothes and find something for themselves to eat, perhaps even do this for others in their family if their energy allowed. The independence that patients gained in being able to do these things for themselves is hugely important.

> I can now fetch water, wash utensils, clothes, sweep the house and courtyard though I am not yet so strong to dig but I can do some work around the home.
> (patient 2 interview 2)
>
> the good things out of the drugs right now I do my work as usual, as I did before I got

> sick but before I got this drug I couldn't do anything for myself.
> (respondent women's patient focus group)

The importance of "digging" to daily life in this rural area was revealed somewhat in that those who were not strong enough to dig, spoke of this with a small amount of shame.

> I: can you give me an example that maybe I can do such and such thing by myself....
>
> R: About that.... (silence)
>
> I: Can you like go to the garden and dig?
>
> R: For digging, the truth is I can't dig, I still feel I am weak...
> (patient 2 interview 1)

Protecting delicate health. The above comment shows that life remained difficult for many patients. However few patients focused their conversation on negative emotions or pessimistic thoughts about the future. It was thought that this could be because many patients described believing in a very strong connection between stress and worries and physical ailments. Very many patients spoke in the interviews about how important it was to their health to cast out negative thoughts and worries. Despite this, many patients expressed that they were overwhelmed by the challenges ahead of them and felt sad about how their lives have turned out. This comes through in some of their statements.

> R: How do I manage? – I can't manage.
>
> I: Does this make you feel disappointed or scared?
>
> R: Now that it has rained if you were to (use) my pit latrine you would also get disappointed – I don't have the kitchen, I'll cook as it rains on me – won't I then feel disappointed?
> (patient 13 interview 1)
>
> Now if someone is counted as the head of the family but you don't have a job to sustain your family, to help them the way you are supposed to do, how would that make you feel?
> (patient 7 interview 1)

> I think about all that and I regret that if I had not got this disease, I would be different because there's no business that I wouldn't manage, digging I was an expert—I left many gardens.
> (patient 10 interview 2)

A very interesting comment was made by the first patient interviewed that lead to further questioning along the same lines.

> Me, I don't have any doubt in my life now, I take myself as a human being. I don't count myself among the sick or those who do not have this disease; I am in the middle there
> (patient 1 interview 1)

After reading this comment, questions were then added to the interview guide which explored whether or not patients thought of themselves as sick or well and also whether or not it bothered patients to know that the virus was still in their blood. When patients spoke of this "sick versus well" dichotomy, patients did not dwell on the fact that they had the virus in their blood. Several people referred to the fact that drugs made the virus "quiet" or "sleep inside of them" and as long as the virus did not bother them, they were not troubled by the fact that it was there. On the whole, patients tended to focus more on the fact that they looked normal and could work as a normal person and therefore did not distinguish themselves from healthy members of the community.

> Yes, I take myself as a healthy person though I know if you checked me you would find me HIV positive but that does not matter, what matters is that I feel healthy and okay. Because I plan, work like any other person full of life, eeehh---- and death is in the hands of God
> (patient 3 interview 1)

Though most patients claimed that they thought of themselves as healthy and normal, it was clear that they did not think of their health in the same way that they did before they became ill. Most patients talked about "this new health" as something that was delicate and in need of protection. They also mentioned that this new health was associated with many rules.

> But me, I always tell them, it is not the end of the road, there is hope to continue living your life though with a lot o do's and don'ts
> (patient 2 interview 2)

All patients acknowledged that they were substantially physically weaker than before they fell ill. Many patients spoke of falling ill from time to time, but they did not concern themselves over these "small sicknesses". Patients said that they did not get worried about these illnesses because they knew that the illness would pass especially if they took the Septrin that they had available.

When patients spoke of what they did to look after their health, some of the talk sounded disingenuous. Some patients may have been parroting what they had been taught at the clinic in an attempt to sound like a model patient. However a great deal of the patients' talk regarding how they cared for themselves was interspersed with other subjects in a way seemed more genuine. These comments were given more weight in the final analysis.

No patient expressed a lack of knowledge or any confusion regarding what they should do to look after their health. However many patients expressed frustration because they were not able to do all that they wanted to keep themselves healthy. The health preserving actions that patients spoke of most often were; not working too hard, eating a variety of foods, avoiding alcohol, avoiding negative thoughts and being careful about sex. Being careful about sex involved: having sex less often, so as not to weaken yourself; and when having sex, using a condom at all times. In the areas of diet and workload was where patients found the most difficulty. Not surprisingly, challenges in this area were purely financial.

Patients did not express that they had trouble getting adequate quantities of food, it was the quality of the food that was a problem. Patients often stated that they did not grow this "good food", good food had to be purchased and this posed a problem. Sources of protein were the biggest concern, with patients often mentioning meat as being close to impossible to get. What made eating quality food even more difficult was the fact that patients could not just purchase enough for themselves. If "good food" was to be eaten, it must be shared with the entire family.

> I: maybe you can convince them and say, "you know for me, let me eat such and such type of food because I am a patient?"
>
> R: Aaah, aah, (No), but the children are solely relying on me, I am the one supposed to provide for them everything.
> (patient 9 interview 1)

Often, patients mentioned that their strength for working in their gardens was reduced compared to before they fell sick. Patients knew that they should come home and rest when they started to feel weak or they would damage their health.

> I can work but not like I used to work before I became sick. That time I would work from 6 am to 4pm, I was a strong man….not like now, I go there and even three hours are very many
> (patient 8 interview 2)

This reduction in the hours of their work financially compromised patients who were already compromised as a result of their illness. In order to feed themselves and their families, many patients were forced to continue working after they knew that they should stop. Many patients spoke about this with distress as they knew that they were doing themselves harm, but did not feel that there was another option.

> now I do a lot of work because I cannot sustain myself and I still have to pay back debts. And I am paying school fees for my children….that's what makes me do heavy work so I can get school fees and after doing this heavy work, I go on getting weak.
> (respondent women's patient focus group)
>
> the pains in body is because of working hard, but I have to work or else I won't get what to eat and I have a lot of appetite.
> (patient 10 interview 2)

There was very little consensus on the issue of changing sexual habits. A number of patients (mostly women, but also two men) said that being diagnosed as HIV+ had put an end to all sexual activity. They had made the decision "not to involve themselves in such things" and that they did not feel the loss of sexuality as significant because it was a small price to pay for staying alive.

In regards to using condoms and avoiding pregnancy, patients answered in ways that would lead a reader to believe that patients felt conflicted on this issue. All patients knew that they should use condoms to avoid re-infection and pregnancy. When asked about their sexual behaviours, patients would often start out by making statements that indicated that they "did the right thing", be it using condoms or intending not to have any more children. But after further discussion, these same patients would make statements that would contradict their earlier statements. While it is only supposition, this could belie the fact that patients knew it was important to describe themselves as practicing safe sex, but found it difficult to comply with what they have been taught in this area. In the men's focus group, many men admitted that they could not bring themselves to use condoms. In the question period at the end of the men's focus group, the topic of conversation focused around sex and reproduction.

> R 1: I have a question --- I am asking if you have a wife and you are both on drugs, can you have live sex? *(meaning unprotected sex)*
>
> R 2: I have Silimu --- I may marry a woman without it – can we give birth to a child and she survives?
> (respondent male patient focus group)

Also two patients in the individual interviews made statements that indicated that the problem of having no children was more serious to them that the problem of being HIV+.

> Aah, aah *(no)*, for me I am not worried about the disease, but what I am worried about is to die without leaving any child, but the problem of having the virus does not scare me at all
> (patient 2 interview 2)

Stigma and status disclosure. As is shown in the above quotations about family size and safe sex, there were a host of social issues that became complicated for patients once they recovered from their acute illness. Coping with HIV stigma and negotiating when to disclose their HIV status were other social issues that patients spoke about a great deal.

In the "HIV era" prior to HAART, issues of stigma and disclosure would have been entirely different. Once AIDS patients had become ill to the point that their infection was visible, their sickness would have progressed until it was fatal. In this way, the amount of time that people had to suffer the shame of HIV stigma was somehow limited. The introduction of HAART has meant that it is now possible for patients to recover from the point where their infection had become visible to others. Now patients must reintegrate into a community where many people know that they are HIV+. There were no patients in this study who felt that their HIV status was a secret known only to themselves. All patients were aware that during the period of their acute illness, their HIV status became obvious to many in the community.

> eh, those first days I first feared for a short time, but when I saw that even if I fear, the people know that I have HIV … so I said let me talk and I decided to be talking about it.
> (patient 11 interview 2)
>
> But people know about this disease, and I am not the first one…mmhhh---- So there is no way I could have hid myself
> (patient 2 interview 2)

Patients in the study repeatedly said that now that they were on drugs they were more resistant to the mean-spirited comments of others. They were now able to disregard those who gossip about them. However, it was obvious that this resistance to gossip was not complete. Some patients still took some of these mean-spirited comments to heart and had to struggle at times to keep their spirits up and find sources of support.

> we are all strong now and we don't care about what people say- let those who wish to laugh- laugh
> (patient 8 interview 1)
>
> Yes now I don't fear those words
> (patient 5 interview 2)
>
> But me I feel I am not fitting in so well, like now if they want to gossip about people

> with AIDS they will not talk because they have seen me
> (patient 4 interview 2)
>
> wasn't she or he about to die?... they continue talking on and on like that. Not all the people around us are happy for us to live
> (patient 1 interview 1)

While all patients made comments which indicated that their HIV status was no longer their own secret, patients also repeatedly spoke of when, why and to whom they would disclose their HIV status. From this, it would be reasonable to assume that patients believed that while there were very many in the community who knew their HIV status, it was not known by absolutely everyone or they would not feel that they had a choice about disclosing their status.

When patients explained to the interviewer which members of their community knew of their HIV status, they frequently spoke of the change in their appearance. When they were sick, it was almost as though patients were wearing AIDS for all to see. Just being seen by others meant revealing your HIV status.

Having gained weight and no longer showing skin rashes were the two changes cited most often when patients described that they no longer looked sick. No longer fitting the stereotypical image of an AIDS patient meant that respondents had gained some control over revealing their status. Now, if a patient met someone who did not know that they had been sick, patients could choose between; avoiding the topic of HIV, telling a lie if asked about their HIV status, or telling the truth, depending on their evaluation of the person that they were speaking to.

> but now I see the change is very great, I have nice skin, I can sit with other people and no one can know unless I tell them that I am sick and no one can point at you that I have the disease.
> (patient 14 interview1)
>
> Yes—now, if someone who doesn't know that I was at one time sick, he cannot identify me as someone who has had silimu, they can't know unless I tell them.
> (patient 10 interview 1)

The Clinical Officer at the CB-ARV clinic made an important observation on this topic when interviewed by the primary investigator. He had observed that many

HAART patients who were single and of reproductive age, moved to a new community once they had recovered. He believed that patients did this in order to be in a place where no one knew that they were infected with HIV.

Being a positive role model. All of the patients in the study explained that because they had the benefit of receiving this life saving medication, they had a very specific role to play in the community. Many patients felt that they were an example of "living well" with HIV. They showed others that it is possible not only to stay alive when one has HIV, but also to look healthy and be productive. Many patients reported feeling proud that they were able to be this role model in their community. In an important way, these patients had turned HIV stigma on its head. Instead of being ashamed and trying to hide their status, patients could now be proud of the fact that they were doing so well despite being HIV+.

> I have to show those people around me that to have HIV virus, you can also live like any other person
> (patient 3 interview 1)
>
> They just cite some examples *(of those)* who have improved after taking drugs and they say, don't you see this and that person, they have taken the drugs and they are now okay.
> (respondent men's patient focus group)

Patients also felt that they had a strong obligation to share what they had learned about HIV in order to help others. Some patients spoke of sharing general information with people who already knew that they were positive. However, it was more common that patients spoke of having to reveal that they were HIV+ in order to communicate the helpful information. Many patients described incidents when they saw someone who had been looking sick and took these people aside in order to talk to them. Patients would share their own story with the ill person and encourage them to go and test. Overwhelmingly that is the help/advice that patients gave to others, not to delay, go and test before getting any sicker. Patients were able to tell their confidant that they understood how difficult testing was, but also that there was medication to help if found to be positive. Patients gave themselves as example of how the medication worked and that there could be life after an HIV diagnosis.

> I got courage when my friends and people around me started asking me questions about HIV, how I feel now that I have it and at first it was hard but I saw people knew I was sick, why should I keep avoiding their questions.
> (patient 2 interview 2)

> I always tell them my experience and encourage them to go. Because I have passed through a lot and I can't just leave people who would have lived to see their future just die. I always tell them.
> (patient 5 interview 1)

Patients placed a great deal of importance on this role. Many felt it was their duty to tell others about how to get help. They felt this because several patients learned how they could access the medication this way. Patients described being very grateful that someone had the courage to confide in them and tell them the how they could save themselves. Patients described feeling happy that they were able to help others in this way.

> whenever I saw someone I told them do this *(go for testing)* giving myself as an example. People like me so much because of speaking the truth, I am okay with people, they treat me well… whenever I go they welcome me.
> (respondent women's patient focus group)
>
> I: eh, how do you feel to see that you can also have people to be helped?
>
> R: I become happy because if I direct them and then they go there and become fine, we can both be happy
> (patient 12 interview 1)

Most patients said that they used a great deal of discretion in choosing who to tell about their HIV status. An important factor that patients considered was how the other person approached them and what that person looked like. Patients said that they felt comfortable disclosing to others who looked sick or who approached them with a quiet, sympathetic air. They avoided telling those who look healthy or were too inquisitive or loud because they felt that these people were asking about their status only in order to laugh at them.

> If someone comes and asks peacefully…."You went to test and they gave you medication, you, how did you get there? Which way?" But I can tell them. But there is this one who comes and jumps on you asking you, her aim is to laugh.
> (patient 13 interview 1)

> Now maybe when someone comes to ask you that I have been told that you have AIDS, now I also have the right to reply that I am not sick because for him/her has not any good intentions.
> (patient 13 interview 1)

Feeling better off than others. When patients spoke about how they were able to dismiss those who would gossip about people with HIV, they frequently invoked a belief held not only by themselves, but by the entire community. This belief was that HIV is extremely prevalent. Patients felt that HIV was so prevalent that most people in their communities had HIV, but just didn't know it yet. Some patients reassure themselves that those who were laughing today, would not laugh for long because soon those people would also learn that they were infected.

> Why, I don't think my life is so different from other people in this village is that these people, most of them are sick though other's have not yet fallen down
> (patient 6 interview 1)

> I don't fear about people saying I have HIV because it has not started with me nor will it end with me.
> (patient 8 interview 1)

It was fairly common for most patients to make comments that indicated that they felt better off than many in their community. Most patients stated that what made them better off compared to others was the fact that they had this medication that gave them strength. Many patients felt that they had been rewarded for summoning the courage to test and "know themselves" because they were now "under the protection of the drugs".

> Me, I have the strength better than them because for them, they feared for themselves and don't know their status, maybe they have this disease but they are scared to go and test. And me, I know I am sick, but I have the medication which is protecting me
> (patient 13 interview 1)

The "others" in the community that patients in the study felt that they were better than was diverse, but generally referred to the whole community of HIV sufferers who had not or were not able to access ARVs. Some patients referred to those who had died in the past before the medication was available. Some patients also referred to those in their community whom they could see were sick, but refused to go for testing. A commonly used phrase for this latter category of people was that they were "choosing to die in ignorance". Lastly, some patients referred to feeling better off than the entire community and they related this to the belief that HIV is everywhere and everyone is infected.

> If the drugs were available then, she would also be living now and since they are available I should *(take)* that chance and use them. I can live for some more time.
> (patient 7 interview 2)
>
> I advise them to go and test and start on taking ARV'S. Some listen and some get ashamed and die in their ignorance.
> (patient 11 interview 1)

This notion of being better off than others was also related to patients' concerns about the continued supply of free medication. Most patients expressed concern that the free supply of drugs, was not sustainable. Therefore, patients felt happy that they were able to test and start drugs while they were still being provided to patients for free.

> but I hear nowadays that they are not giving anyone going for testing medication, the project stopped, but for us who did not wait to be pushed have gained a lot in these drugs. I am healthy now.
> (patient 3 interview 2)
>
> I think only these that have not yet tested or started the medication are the ones to worry even more because the sick people are many and maybe in future people may be told to buy their own drugs.
> (patient 1 interview 1)

These "better off than others" comments when combined with the fact that many patients were proud to be an example and a resource for their community would indicate that patients had at least partially overcome HIV stigma. They no longer described feeling shame and inferiority with respect to their social position. While no patient stated this directly, it may also be possible that after HAART, patients felt less vulnerable to HIV stigma because they had defied the content of the stigma itself. The gossip that patients reported hearing about themselves and other HIV suffers was that they were useless, bound for the grave and so thin that they could be blown by the wind. It was also possible that, patients felt more resistant to this stigma because it no longer applied to them; they had gained weight, could do their work and did not seem likely to die any time soon. This "triumph over stigma" was of course incomplete as mentioned previously, many patients still felt the sting of being mocked and excluded.

Finances and goals for the future. All of the patients in the study had children except for two who were childless. Patients with children would repeatedly speak about how concerned they were about the condition their families' would be left in after they died. Patients stated that during their illness this was a very important concern and would cause them a great deal of distress when they thought of it. Many patients described feeling that they were being taken before they had a chance to plan for their children. Now that patients had been given a "second chance on life", they felt it was very important that they use this opportunity to plan so that they did not find themselves in that situation again.

Not surprisingly, the ultimate goal for all of the patients in the study is for their children to be self sufficient. Most parents around the world want to know that their children will be able to look after themselves after they have died, and the parents in this study are no different. While patients spoke often about monetary planning, they were also very happy that they could carry on parenting and protecting their children who were still young and vulnerable.

Patients had very specific hopes for what they would like to accomplish in order to "leave their children well". All of the patients' plans had a great deal of similarity and had two main priorities. Patients hoped that they could leave their children with secure housing and also with a continued income source. A priority regarding housing was that the home must be on land which is not rented, but owned in such a way that the inheritance of the land cannot be contested by other family members.

> I had also told you about buying land. This is the most important of all because if God wills and you have to die- you leave your children when they have a place to be (patient 4 interview 2)

There were two things which patients hoped to do to in order to ensure that their children would be able to support themselves in the future. The first was to continue to pay school fees for their children. Educating their children was hugely important to patients Secondly, parents wanted to be able to leave their children with a source of food and/or income. Generally this meant leaving a plot of land so that their children could grow and sell their own food, but some patients also hoped to be able to leave a business.

These plans for how patients would leave their families' were referred to as "development plans" and patients said that they were a frequent topic of conversation with other members of the community, both those they knew were also HIV + and those who were not known to be HIV+. It is likely that development plans were such a popular topic of conversation because they were fairly common to everyone in the community and always a challenge to accomplish. While this was not a focus of the study, it may be safe to assume that the development plans of HAART patients were very similar to plans of non-HAART patients.

With respect to their development plans, the HAART patients in the study were likely different from the rest of their community in two ways; they were starting their planning from a disadvantaged place and they had an impaired ability to do their work. Many patients sold property and went into debt during their illness in order to generate money needed for their treatment. Also, as was previously discussed, patients had been left weakened as a result of their illness and could no longer spend as much time tending to their crops as they could before. This has reduced their ability to feed their family and also generate income. If "development planning" were compared to a foot race, it is almost as though these HAART patients had to start from farther behind and run much more slowly in order to get to the same place as other members of their community that had not been sick.

> You know when you are okay without any problem … you count much time in the future for you…….. But when my wife died that is when I saw the need to prepare for our children --- *kept quiet* ---- mmmhhh---- its now that I see it is important to build and educate my children and I don't have a job
> (patient 7, interview 1)

In order for any person to financially plan for their future, they must have enough money to meet their present needs as well as some left over to put towards future goals. Very many patients in the study made remarks that seemed inconsistent with respect to their development plans. When patients were asked if they were optimistic about their ability to accomplish their plans for the future, almost all patients responded that they were. Most patients felt encouraged by the amount of financial progress that they had been able to make in the time since they started they HAART and felt they would be able to continue to improve on their financial situation and eventually achieve their goals. There were only two patients who were more pessimistic, saying that the financial challenges in front of them were very great and they did not see how they would be able to overcome them.

However these same patients who were optimistic about their ability to achieve their development plans also expressed a great deal of concern about meeting their own daily needs. Anything that required the spending of cash remained a huge problem. One of the patients' children had recently been sent home from school because school fees had not been paid, many other patients spoke of about the precariousness of finding money for school fees. Also finding money for "good food" and transport remained a huge problem. The explanation of this seeming inconsistency was not explained.

When talking about their development plans, patients more often made vague comments about what they wanted for the future.

> I want to send my children to school, I want, let's say I buy for them a cow and also for it to be there and let's say I have got money to buy another piece of land to expand.
> (patient 13 interview 1)

Than comments that would indicate that they have begun to take action on their developments plans.

> I have already bought the plot, iron sheets, I am bringing bricks and I will start to build a permanent house so that it can stay longer even after I am gone.
> (patient 3 interview 2)

It is possible that the predominance of vague statements over concrete plans when patients spoke of their development plans may be due to the fact that the steps that needed to be taken in order for patients to achieve their development goals were not attainable for patients in the near future. This could be due to the fact that patients had only started HAART recently and if given more time, would be able to act on these plans further. However, it may also be possible that these plans would never be possible for these patients given the financial situation that they were in.

Family instability. It is not only the financial consequences of illness that continued to hamper patients' lives once they had regained their health; challenges persisted with respect to family relationships as well. From the stories told by the patients, it seemed that HIV introduced conflict and instability into families in a way that HAART could not remove. In the time when the patient was sick, relationships were broken because of death and conflict, and rarely was it possible to mend these relationships. Patients were left to carry on with feelings of loss and hurt. Often patients had to function in families where a member who had provided a significant source of support had already died of HIV. This was very true of the single women in the study. However the two widowers interviewed also said that they felt the loss of their wives acutely. Financial matters and issues of childcare were the areas which posed the biggest challenges.

> It hurts me so much, it caused me a lot of pain if he *(my husband)* hadn't died, he would have lived with the help of the drugs.
> (patient 14 interview 1)
>
> I: Now can you give me the picture now, if your wife was still alive, what would you hope her to be her responsibility for your home.

> R: A lot, because the business we used to do, the digging, maize dealings, she was the one running all this and the home also. To see that we are also self-reliant she would run all that responsibility ....eh! Now I can't manage to even go far for business (patient 9 interview 2)

There was only one case in which a patient was able to forgive her parents, thus re-gaining their financial and instrumental support as a result.

> I would feel angry especially when my parents refused to help take me to the hospital. I would remain in isolation, by myself. But when I went to the hospital and got treatment, I forgave them.
> (patient 5 interview 1)

One patient told the story of how she was badly neglected by her husband when she was sick. She said that her husband refused to care for her and worse went around telling people that she must have HIV. He also said that he did not know where she would have gotten it from because he was not infected himself. This situation caused her to leave her husband and return home to her parents, taking two of her three children with her. Now that she has recovered, her husband is now asking for her to return to him.

> He thought I was going to die, but I lived and am looking good and can work
> (patient 1 interview 1)

She refused to return to him and occasionally heard that her oldest daughter who was left with her husband was not well cared for. This patient was forced to carry on with the pain of having being neglected by her husband as well as the pain of wondering if her child was being taken care of. Though she was living with her parents, the fact remained that she was now a single mother and ultimately responsible for two young children. She was too sick to work in the garden, but sold goods at the market to make money.

In two cases, not only were family conflicts not resolved by the introduction of HAART, but fighting in the families actually increased. The most dramatic example of how family conflict increased after the patient started HAART was in the case of a single woman who left her family after they had tried to kill her by way of poisoning her food. The woman believed that her mother and her sister put poison in her food because they had thought that she would die when she had AIDS, but now that it became apparent that she would not die, they had tried to kill her. The patient said that she could not understand why they would do such a thing. She thought it may have been because they were afraid of catching HIV from her or because they wanted the land that she had inherited when her father had died.

> *(when I started improving after taking HAART),* that's when my mother and sister started giving me hard times, the care was no more, they said I was eating food for no good reason…. I will be eating food for nothing because I cannot work- I am too weak to work, that is what they say.
> (patient 10 interview 2)
>
> she hates me because she says with this disease I am of no importance to her, that I should even die and she can have peace.
> (patient 10 interview 1)

While this story does seem very dramatic, it was corroborated by her brother who was interviewed as her caregiver as well as the Volunteer Health Worker. The RA who interviewed this woman was convinced that this was a true experience.

This woman was the most destitute of all the patients interviewed. She could not live with her brother as he was already supporting another brother's orphaned children. She stayed in an abandoned house and had no possessions. She was very hurt by the actions of her mother and sisters and was extremely emotional when talking about them. She was living almost entirely without financial support and only had the emotional support of her brother and sympathetic family members.

> I: How do you feel being sick and having a mother who neglects you and treats you like that, what thoughts does this make you have?
>
> *(becomes emotional and tears in the eyes)*-----------------------------------
>
> R: I think hard and even ask myself what wrong on earth have I ever done to my mother and I can't find the answer, my heart then beats very fast, I get headache and tears start running down—I can't understand all this.
> (patient 10 interview 1)

While instability in family relationships was mostly introduced as a result of illness, there was also a certain amount of instability for patients as a result of recovery. Four of the seven patients who were forced to move in order to live with a caregiver when they were sick, recovered to the point that they were able to leave that situation and live once again on their own. Two other patients expressed that they also wished to leave their parents' home and find an independent living situation if they became healthier and more able to work.

> Eeeh ---- you see me I was not staying here *(before I became sick)*, my mother is also married here, so I feel I am inconveniencing her here, it is better I also get my own home and establish myself in my own home.
> (patient 6 interview 2)

> And when this wife comes, do you think I will take the woman to my mother's house--- no, it is not good...*(laughs)*
> (patient 7 interview 2)

5.2 Caregivers

Description of Respondents

Table 2. Description of Caregiver Respondents

Age	13-17- 4 17-30 - 3 30-60- 7 >60 - 1		Relationship to Patient	Child- 4 Mother-5 Spouse-4 Sibling-2
Sex	Male – 5 Female – 10		Change of Household Membership Prior to HAART	Yes- 4 No- 11
Religion	Christian-14 Muslim-1		Still Living with Patient	Yes- 11 No- 3
Level of Education	None- 2 Some Primary- 13		Ever Tested for HIV	Yes -5 No- 9
			HIV Positive	Yes-4 No-11

As has been described in the Patient section of this paper, the acute illness experienced by patients introduced an element of instability into the patient's family life as he or she was forced to move around in order to find adequate care. Patients were well aware that the burden placed on their family network by their illness was severe and threatened to overwhelm the family's coping mechanisms.

In 11 of the 14 household's interviewed, the patient's acute illness provoked a change in household composition which was needed to meet the care demands of the patient. In some cases, the patient moved in order to be close to a family member who was willing or able to be their caregiver. In other cases, caregivers would move in order to be close to the patient.

The households that remained most stable throughout the patient's illness were intact married couples. The four married couples interviewed, did not describe gaining or losing any household members during the patient's illness. However, these families experience a different type of stress because all of the caregivers in these situations were also HIV positive. All of the caregivers interviewed were also starting to experience failing health, though to a lesser extent of that of the patient.

In all households, there was one person in the household who was primarily responsible for the patient. Where child caregivers were involved, the child was expected to assist another female member of the patient's extended family when the patient was sick and then was left alone with the patient once the patient became well.

The households in the study were placed into a state of chaos by the patient's illness. Grandmothers were forced to take back their AIDS sick adult children along with their grandchildren. Children had to do the household work normally done by adults and spouses less sick with AIDS had to care for spouses more sick with AIDS. When patients began to physically recover after commencing HAART, much of the stress placed on these tenuous family coping mechanisms was relieved.

In six of the fourteen households, the physical recovery experienced by the patient produced another change in household composition. Patients moved away from caregivers in order to gain independence and reduce the burden on their families. In cases involving child caregivers, the adult caregivers who had come to assist these children, moved back to their own homes.

From this description, it is obvious that the families in this study were forced to cope in whatever way they could in order to provide a supportive environment for the patient. The ways that they responded to this extreme chaos were varied and depended largely on the composition of the patient's extended family network.

There were four main types of care giving arrangements; spouses, grandmothers, child caregivers and siblings. Four spouses were interviewed as caregivers for their partners. Two of these spouses were wives caring for their husbands and two were husbands who had done care giving work for their wives when their wives were ill. All of the couples in the study were concordant and both partners were taking HAART. In all cases, the male spouse fell sick, tested and accessed HAART before their wives became seriously ill. The oldest of the caregivers fell into this category and was a 63 year old woman, caring for her 65 year old husband.

Four teenaged children were interviewed related to the care giving work that they had done for their parents. The youngest of these respondents was a thirteen year old girl who had cared for her father and the oldest was a 17 year old girl who cared for her mother. The middle two respondents were boys. All of the teenaged caregivers were "single orphans" and had one parent who had died of HIV, with the remaining parent on HAART. All but the oldest of these teenaged caregivers also lived with their siblings.

Five of the caregivers were older women caring for adult children. In all of these cases, the patient had been living independently of the caregiver, but returned to their mother's home when they became too sick to care for themselves or were abandoned by their spouses. In the cases of three of these patients', the adult child brought their own children with them to their parent's home.

Lastly there was one brother and one sister interviewed regarding their care giving work for their siblings. Both of these siblings lived with the patient when they were ill. Now that the patient was more independent, these siblings no longer live with their patient, but still feel obligated to support the patient as much as they can.

Given that there was so much variety in the caregivers' experiences, it was not possible to produce a chronological type narrative which was common to all caregivers. The great variation in the caregiver sample did not allow for these generalizations to be made in the same way that was possible for patients.

However all of the caregivers did share a high degree of care and concern for their patient. They also shared a feeling of responsibility for their patient's wellbeing, which led them to take action on the patient's behalf. It was this sense of responsibility for the patient which united caregivers and allowed common themes to be found amongst their experiences. These themes will be described in the following sections.

The discussion of common themes in the caregiver interviews will be divided into three sections as opposed to the two sections used in the discussion of the patient results. The first section will review some of the important ways in which the caregivers described similar beliefs to the patients. The second and third sections will be similar to the patient's discussion in that they will review the Caregiver's description of the pre-HAART era and then the description of the changes which occurred after the introduction of HAART.

Caregivers Echo Patients' Beliefs

On three key issues of death, social stigma and family finances, caregivers and patients expressed views that were very similar. This may have been because the beliefs expressed by the patient and the caregiver were reflective of beliefs held at the community level, however this was not a focus of the study. It was also true that four of the caregivers were also HAART patients themselves, so it was very likely that their own experience has had an impact on their thoughts and beliefs.

Thoughts of the patient's death. When the patient was acutely ill, caregivers described feeling as though the patients' death was certain and imminent. Caregivers were also very afraid that that patient would die a "bad death" with excessive diarrhoea, weight loss, skin lesions and a great deal of pain and suffering. Surprisingly, caregivers did not comment on what the patient's "bad death" meant for themselves, only that they were afraid on behalf of the patient. After the patient settled on their medication, caregivers shared the patient's confidence that the patient would live for a good amount of time in the future. Again caregivers were reluctant to specify the number of years they felt that the patient had left. Many caregivers said that they put thoughts of the patients' death out of their minds and instead focused on thoughts about the patients' life.

> I: But now how do you feel exactly, are you a bit relaxed seeing your son taking his drugs and his health improving?
>
> R: Now I can count days for him I know he is going to live to see that I told him to take his medication.... I can't control death it is a law. But now I cannot count for him days. That he might die in three days time or at the end of the day. *(No)*. He still has his energy.
> (caregiver 7 interview 2)
>
> About the future of her life, God knows. I am not God. Because they say these drugs do not cure completely. Time will come and God will take her, but now she is now fine and she looks good.
> (caregiver 6 interview 1)

When asked about the type of death they felt the patient would experience now that she/he was taking drugs, all caregivers felt that a death on drugs would be more peaceful, and fraught with less suffering than a death without drugs.

> I: What do you think about her death now, do you think she will have this bad death people talk of or what do you think exactly?
>
> R: She will die peacefully; she will sleep and die
>
> I: How do you feel that your patient will die looking healthy?
>
> R: I feel happy because I know people will not run away from her.
> (caregiver 10 interview 1)

This also points to the great faith that caregivers had in the power of ARV medication. Similar to patients, caregivers felt confident that these drugs were powerful and would always work to protect their patients. The only fear that they had is one also shared by patients; that the drug supply could be stopped and their patients would again become very ill and die.

Stigma and disclosing the patient's HIV status. When discussing what other community members knew about the patients' HIV status, caregivers and patients were agreed that many in the community knew of the patients' status through gossip or guessing from the appearance of the patient. Almost all caregivers were similar to patients in that they said they would only disclose the patients' HIV status if they thought that this information would help someone else who may also be in need of ARV medication.

> Some people you can tell and you know you trust them to take it as a lesson or something important but others *(that)* you tell can go on talking like the wife of that man is stupid --- she has decided to remain with a man sick of AIDS...... if I were her I would leave that man to die alone --- they say so many things which would hurt you and you end up becoming enemies. Me I can only tell someone trustworthy who also will make use of what I have told her and go to test.
> (caregiver 3 interview 2)
>
> There are some people who genuinely ask to know or they want to understand what *(the patient)* passed through. Those one I usually tell them the truth. But there are some who are looking for what they can gossip about, I usually push them to her to ask her because she knows better. Some people they ask because they need the courage, and those who could be sick and are scared to go and test, for those ones I usually tell them and encourage them
> (caregiver 6 interview 2)

The only exception to this was the teenaged caregivers who were extremely secretive about their parents' HIV status and did not feel comfortable sharing this information with anyone, at any time. When speaking on this topic, teenaged caregivers spoke of keeping their parents' HIV status a secret in order to avoid teasing from their own peer group.

> I: What do you tell your friends about your mother's illness do you tell them that your mother has this virus and may be she will die?
>
> R: Some of them know, they are our neighbors they even told other children at school, I stopped playing with them, I don't go to fetch water with them any more
>
> I: How did it make you feel, your friends telling other children about your mother's status?

> R: I just kept quiet.
> (caregiver 5 interview 1)

Not surprisingly, caregivers also described their community as being divided into two groups; those who are supportive to people with HIV and their families and those that chose to judge and stigmatize those affected by HIV. Caregivers described being more vulnerable to gossip and the judgement of others in the time before their patient began HAART. Some caregivers described many people stopping by their homes, offering assistance and kind words. Other caregivers described being pressured by others to abandon their patient. After their patients had recovered, caregivers seemed much more resistant to the gossip and of community members. Caregivers seemed to be able to draw on the support of their families to resist the damaging effects of this social pressure. Six of the 15 caregivers interviewed described feeling proud of their successful care giving work and felt that they could be a positive role model to their community.

> And I even hear some people talking about me that I am a strong woman if it were another one she would have ran away from him. Me I care for him, I think am an example for people around this area, because some people really appreciate what I am doing.
> (caregiver 3 interview 2)

> Haa… *(Is happy and smiling)* at the moment as you move around you can hear people saying I am the President because I saved someone from death, people appreciate and most have come to me for advice, asking how I managed to bring someone back to life.
> (caregiver 10 interview 2)

Household finances and goals for the future. With regards to financial matters, patients and caregivers were once again very uniform. They both spoke of the great financial problems caused by the patients' illness, of having to sell possessions or borrow money to generate the cash needed for medicines or transport. Caregivers also had the same goals for the future as their patients. The caregivers' hope was also to leave their children as self sufficient as possible. This meant that their priorities for the development of their family were to pay school fees, secure permanent, adequate housing and expand their garden plot so that their children could use this as a source of food or income in the future.

Context for HAART Changes

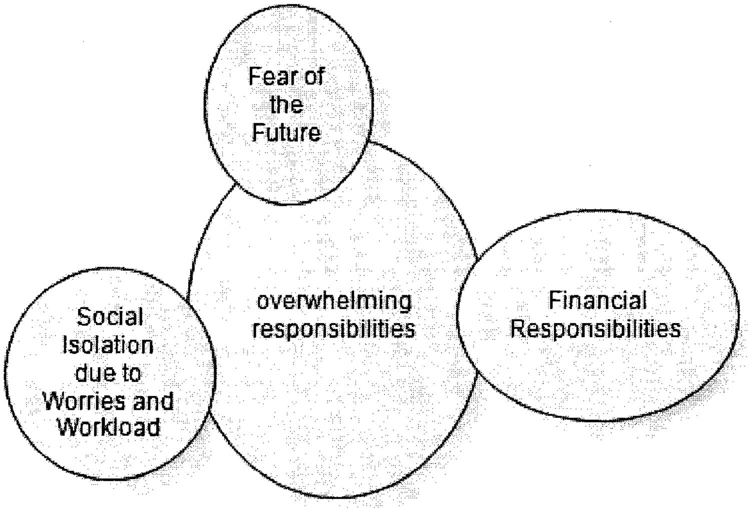

Figure 3. Context for Caregiver Changes after HAART.

When asked to describe their thoughts and feelings during the time when they were caring for their patient, all caregivers described feeling scared, alone and overwhelmed. Caregivers had to cope with meeting the needs of everyone in the household, however all caregivers prioritized the needs of the patient above the rest of the family. There was a great deal of commonality in the list of responsibilities and how caregivers chose to manage them. As a result of these high levels of stress, caregivers described feeling socially isolated. Many caregivers spoke about the levels of stress as being at such a high level as to be unsustainable.

Overwhelming responsibilities. Caregivers were asked to describe the list of their responsibilities during the time that the patient was sick. Issues related to finding money and feeding the patient were discussed most often by adult caregivers. Only one child caregiver felt responsible for raising money. Not surprisingly, men spent more time talking about finding money for the patient's transport and medicine, but this was also a preoccupation for women. Surprisingly, all but one of the men described doing domestic work when it was required of them with little difficulty or shame. One of the Research Assistants told the primary investigator that this was a cultural trait common to the Bakiga, who were a dominant tribe in Rwimi sub-County. All of the adult caregivers interviewed were not only responsible for the patient, but also for the other members of their household as well as tending to the family plot. Children described being responsible for many of the household chores as well as going to school and tending to the family plot.

Feeding the patient was often the very most important task. However this task was made extremely difficult by the fact that the patient had very little appetite. Because the caregiver did not know what the patient was suffering from, it was thought that perhaps good food could cure the patients' sickness. It was therefore important that the patient be given appetizing foods, considered to be of a "healing nature" or of good quality. This often meant that the food had to be purchased. Therefore the caregiver was also charged with the responsibility of finding money in order to buy this good food for the patient. Caregivers also had the responsibility of washing clothes and bedding for the patient and in some cases toileting and bathing the patient if he or she was too weak.

> you get worried that he is dying of hunger, so you first cook, give him what he feels like eating, go out get something good for him to eat.
> (caregiver 4 interview 1)
>
> Yes, by the time we took her to the hospital, we were bathing her, helping her to walk, washing for her.
> (caregiver 6 interview 2)

The caregiver also described having to tend to the rest of the household which involved cooking for the other family members as well as fetching water and firewood. In many cases, the caregiver would have to look after the patient's children as well as the patient themselves. Digging in the garden was also the primary responsibility of the caregivers.

> I would get worried about her children and this small boy was still very far *(young)* …. *(he)* came when *(he)* was even breast feeding…. I was the one sleeping with him!

> When crying and wanting to feed, all that was my responsibility.
> (caregiver 1 interview 1)
>
> I felt hurt but because I was the one available. I took the responsibility to care for this patient and her own people and even to also care for my family.
> (respondent women's caregiver focus group)

Female caregivers described putting their own needs last behind the needs of the patient and the rest of the members of the family. Many female caregivers said that there were many nights that they could not sleep, either because the patient needed round the clock care or because they were so worried that they could not sleep. All caregivers also described having no time to rest in the day and not being able to eat well, either because they were too busy to eat or because they had to feed the rest of the family before themselves. It must be kept in mind that at least four of these caregivers were HIV positive themselves.

> the other time, sometimes I would not sleep because he would groan all night "I am dying I can't breathe…" such things and I would not even get into bed and sleep
> (caregiver 2 interview 1)
>
> Me, I would not even sleep well or even eat well, there of course I lost my weight and you could see my all bones in the chest ……. *Laughs* ….. I would work so hard and get so tired …..
> (caregiver 7 interview 2)

Another aspect of self care that all caregivers neglected was socializing. Going to visit family and friends often involved long trips away from home and there simply was not time for this activity when the patient was acutely ill.

Financial responsibilities. Another important responsibility for adult caregivers was to find money for the patients' transport and treatment. Because the patient was so ill, it often fell to the adult caregiver to sell off family property or borrow money in order to get the patient to the clinic or purchase the needed medications.

> I also used to try by all means to borrow some money. That is why I told you that I

> have a lot of debts. I wanted to make sure she is also looked after very well.
> (caregiver 11 interview 1)
>
> She came to me three times while crying, asking me too take her to the hospital saying "my brother I am going to die, please help and take me to the hospital". I told her, I don't have money, I told her that the first and second time and on the third time, my wife said she can borrow money from the money lending project so I can take her to the hospital and she did. That's how I managed to take her to Rwimi clinic, on a bodaboda *(motorcycle).*
> (caregiver 10 interview 2)

Though caregivers would try their best to tend to everything on their long list of responsibilities, often it was impossible and caregivers would have to choose which activities were a priority and which could be left undone. The activities that were left undone were those that would take the caregivers away from the home for an extended period. Many caregivers said that they were scared to go away from home lest they return to find that the patient had died while they were away. This meant that many caregivers neglected their gardens during this time. Not only was the growing of food neglected, but going to the market to sell excess produce was also not done. This meant that caregivers had the double financial burden of trying to raise extra funds for the patient while at the same time coping with reduced income for the family.

> When I could reach there in the market and don't settle because I have left the sick person at home. So I would not have peace until I left the place.
> (caregiver 3 interview 1)
>
> I: Mmm, now during that time you were looking after her, are there some of the things you would give up doing because of looking after your sick wife?
>
> R: I had planted Maize but I didn't cultivate anything from the garden.
> (caregiver 11 interview 1)
>
> Yes, because if you have a patient and she is groaning you cannot go out to work, you have to look for money which is also not easy to get…
> (respondent men's caregiver focus group)

While only one of the four child caregivers was responsible for raising and borrowing money for herself and her mother, children were also affected in their age appropriate "work" by the patient's illness. Two of the school aged caregivers reported that they were unable to attend school for brief periods in this time because the family was unable to raise school fees. Two other teenaged caregivers said that they were kept home from school on days when their parent was very sick in order to tend their mother or father. These same children stated that if they did go to school when their parent was ill, it was very difficult to focus on their school work for fear of coming back home to find that their parent had died.

> I: Whenever you would go to school and leave your Mum sick at home, did you use to settle in class and listen to what the teachers were telling you?
>
> R: Mm. (no)
>
> I: You tell me how you were feeling?
>
> R: I used to think that maybe one day I will find my mother dead at home.
> (caregiver 5 interview 1)

Isolating worries. Caregivers often stated that they felt very alone during the time when the patient was sick. This was partly due to the caregivers' reduced contact with others as a result of being tied to the home by their work, but caregivers also said that they felt very isolated because of worry and stress. Caregivers were consistent in describing their loneliness during the time of the patients' acute illness. Many caregivers said that they felt overwhelmed by "thoughts". They felt alone with these thoughts, as though no one could understand all of their fears.

> I: You told us that, that time when *(the patient)* was sick – very sick, you would feel alone – lonely, was it because people could not come to visit you or ---- why did you feel like that -----
>
> R: I had a patient and people would come to visit and you know that whole time you have a lot of thoughts on your head ---
> (caregiver 1 interview 2)

The majority of caregivers reported being wracked by fear when the patient was very sick. However, there were two caregivers who said that they were never scared because they knew the drugs were available and would save them from this unsustainable situation. Most caregivers were in an extremely precarious emotional state when the patient was ill and described this time in vivid detail. Firstly, most caregivers were sure that their loved one would soon suffer a very difficult and painful death. Caregivers were also scared of seeing their loved one suffer and die in such a way, especially because they felt that they were responsible for preventing this from happening. Caregivers describe being in an impossible situation, not only was it almost impossible for them to provide adequate care for the patient, given their circumstances, but even if they were able to provide this care the patient's illness continued to advance unabated. Therefore the failure at their task was unending. This was true whether or not the caregiver suspected that the patient was suffering from HIV.

> I: For you inside, did you feel you were blaming yourself that you should have done this?
>
> R: Mhhh! It would also happen because I tried and took her to the hospital, clinics, but I would see that the sickness was not going back, but it was continuing to go forward.
> (caregiver 1 interview 1)
>
> I felt worried and sad and whenever I could watch him in that condition, I would remember those that had died because of the same disease this caused me to fear and think a lot without any solution.
> (caregiver 4 interview 2)

Fear of the future. Given that many caregivers felt certain that the patient would die, another great fear that plagued caregivers was the fear of what would happen to themselves and the rest of the family after the patient had died. In all but three of the families interviewed, the death of the patient would have considerably worsened the family's financial situation (compared to before the patient became ill). This fact weighted heavily upon the caregivers. Families were already in a financial crisis due to the illness of the patient and caregivers recognized that they would be left alone to try and find a way out of this financial crisis once the patient died. Grandparents were worried about being left with additional grandchildren to support, wives worried about where they would live and how they would support their children on their own.

> I am a mere widow without a husband, I would ask myself now if he dies like now what I am I going to do with the children. These children are still young and now have become orphans. Then I would feel so bad.
> (caregiver 7 interview 2)
>
> I would feel dizzy with worries and have no appetite. I didn't have any energy in my body, I had lost hope, like that- that was my weakness...... I would feel lonely, always thinking he is going to die and leave me and the children in the house of rent. I was scared and had nothing to do or even what to think...What solution?...I was there confused.
> (caregiver 3 interview 1)

Child caregivers especially told of their fear of being left alone after their parent's death. They were well aware that they would become the head of a household of orphaned children.

> I: Can you now tell me what exactly happened when your mother died.
>
> R: She died when daddy was also very sick and we thought he would also die and we remain orphans.......
>
> I: You said you have an uncle wouldn't he help you?
>
> R: He can help me but he takes long before he helps me.
> (caregiver 9 interview 1)

Changes after HAART

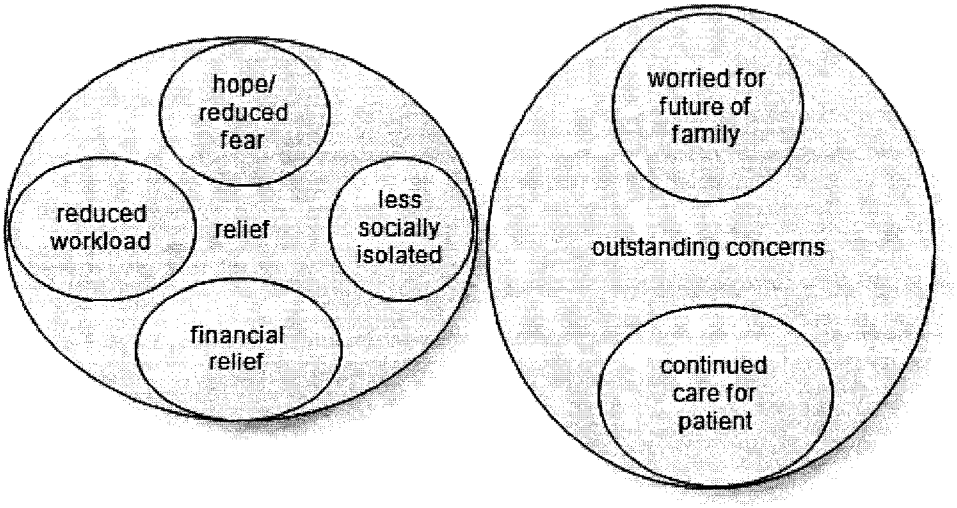

Figure 4. Caregiver Changes after HAART

As is true of any family crisis, the amount of effort needed to maintain general functioning in the household in this time was so high as to be unsustainable in the long term. Indeed this was how caregivers described the situation prior to HAART. Caregivers described feeling exceptionally grateful for the arrival of HAART as they felt that they were nearing a breaking point, that things in their home could not continue in the way that they had been going.

> We had reached a time when we were fed up and said no, but when you came in, you helped us.
> (respondent men's caregiver focus group discussion)

While the situation for the caregiver was vastly improved, caregivers still do not describe their present situation with ease. It seems as though things in their households have improved from unsustainable to varying degrees of difficult. In all cases, the sense of needing to care for the patient remains, but the amount of obligation that the caregiver had to the patient varied. The level of obligation was determined by the health status and amount of independence that the patient was able to achieve.

In discussing the changes that HAART has brought into their lives, caregivers spoke of how the burden of their day to day responsibilities was reduced, but not eliminated because the patient was still in need of special care and concern. Caregivers also described that their fear of the future was greatly reduced, but again, not entirely eliminated.

Relief of overwhelming workload. As would be expected, caregivers described enormous relief due to the fact that their day to day responsibilities were reduced. Though in most cases, the caregiver still felt an obligation to tend to the patient; they were no longer stretched to the breaking point in a losing battle against the patient's illness. The single biggest factor that relieved the caregiver was that the fact that the patient could now perform many daily activities for themselves. Caring for the patient took up so much of the caregivers' time that very many other household tasks were neglected. Caregivers no longer had to make impossible choices between household chores that were all essential to the functioning of the family.

> Yes, because *(now the patient can)* help to change, to wash, to cook for her tea and all this was my work but now I can go to the fields and do the digging up to the time I want because also for her now she can do most of the work for herself, she can cook, eat lunch, supper or even go to do her other businesses.
> (caregiver 1 interview 2)

The most important thing that the patient could now do for him or herself was feeding. Now that the patient had gained strength, this relieved the caregiver of having to prepare all of the food for the patient as well as search for money in order to purchase good food. Caregivers described being relieved of the responsibility of feeding the patient as being hugely important to the reduction of their stress levels. While ensuring the patient ate a healthy diet was still a priority for the caregiver, in most cases, once the patient had recovered, she or he ate the same foods as the rest of the family. Caregivers also described doing a larger share of the domestic chores so that the patient could rest, but in most cases, the patient had the strength to resume their share of the cooking and cleaning.

> I help her to look for firewood and when I see she has no energy I go to fetch water for her. But she does other things like cooking and washing..
> (caregiver 11 interview 1)
>
> I have to know that if she has been doing something and now she is sick and can't do it that I have to do it
> (caregiver 11 interview 2)

Caregivers are relieved of their financial responsibilities in three very significant ways. Firstly caregivers no longer had the task of trying to generate cash in order to pay for the patient's transport and medications. All of the destabilizing expenses of illness have ceased. Secondly, now that the patient no longer requires round the clock attention, caregivers were free to return to their agricultural activities. This meant that caregivers could tend to their gardens, which meant more food for their families. This also meant being able to sell their produce at the market, which generated much needed income. Lastly, the patient was also able to resume some level of productive work, so caregivers had help in the garden, or the reassurance of a second income stream for the family.

> Then when he saw that he is earning he stopped me from working *(outside the home)* … I can only do the work at home. But for him, he is working in that his job and bringing money home.
> (caregiver 3 interview 1)

Relief of worry and presence of hope. Though caregivers are still concerned about the well being of their patient, the amount of worry experienced by the caregiver has reduced enormously from when the patient was sick. Even when the patient fell sick with opportunistic infections, caregivers now felt confident that this illness would pass and the patient would recover. The weight of worrying about the patient's health and the functioning of the rest of the household was a heavy burden and caregivers now describe being freed of that burden. Though caregivers still had concerns and problems, these problems were much more manageable than before. Caregivers now described feeling strong and peaceful about their situation. Above all, caregivers celebrated the health of their patient. They are relieved knowing that their loved one would survive and was no longer suffering as before. Caregivers were now free to hope for a better future, whereas before HAART, this optimism was not possible.

> he started sitting up and I started saying "God is great", this person is even going to stand up and later when he stood up I felt very happy and all the thoughts ceased.
> (respondent women's caregiver focus group)
>
> all this encourages me to even start seeing in the future that we will develop ourselves and our family generally.
> (caregiver 3 interview 1)

Relief of social isolation. Caregivers were definitely able to socialize much more they were when the patient was ill. When the patient was ill, caregivers described being tied to the home, because of fear for the patient and heavy workload. After the patient's recovery, caregivers no longer staid at home for fear of returning to find the patient dead. Caregivers were also much more free because patients were able to care for themselves and sometimes even other members of the household. Many caregivers described having the ability to get involved with church activities. Several other caregivers said that they were now able to go and visit relatives or join cooperative organizations. Caregivers also reported being well received by friends and family when they go out to visit.

> Yes, now I can go to visit. I am not worried who will cook for her, she can cook for herself.
> (caregiver 6 interview 2)
>
> I even go for prayers--- I go to Fort Portal for prayers and leave him here --- he has no problem, he is now calm. ….I have no problem – I feel okay and people give thanks to God for our lives saying God will never abandon his people.
> (caregiver 3 interview 1)

A very important source of support for the caregivers was patients themselves. Caregivers described being very grateful for the support that patients were able to provide. Prior to the patient's recovery, caregivers said that the tremendous burden of their fears and worries was very isolating and that they felt very alone in the world. Presumably, they did not share their worries with the patient because the patient was too ill to be able to cope with this stress. After the patient's recovery, caregivers spoke of being part of a team, together with the patient. There was a sense of reciprocity between the patient and caregiver that did not exist before. The patient could help the caregiver with their work if they became too tired and likewise, the caregiver often helped the patient. Though caregivers were aware that the patient was not exactly a "fully functioning" member of the team, many caregivers said that they felt more relaxed in part because they knew that the patient could now look after them if they needed help. This was especially true in the case of child caregivers, they described feeling much less vulnerable because there was once again an adult that they trusted in the home who could care for them.

> Now --- I think that we can help each other in any way, if I am sick she can also get me sugar, that nice food that I want to eat. In anything that I have not been able to do she can help me be done
> (caregiver 1 interview 2)

> I like that very much, so that I can also do something to contribute on what he is doing so that we can plan well our everyday life----
> (caregiver 3 interview 1)

Continued care for patient. Though relief was the most prominent theme in all of the interviews with the caregivers, there was a wide continuum with respect to the amount of responsibility that the caregiver still had to the patient. In only one situation was the patient, an adult male able to achieve total independence from his mother whom he had returned to live with during his illness.

> What do I have to do for him, he no longer lives with me...but if he comes and there is food he can eat ... he eats and then goes.
> (caregiver 4 interview 1)

In two other situations, the reduction of responsibilities of the caregivers was very minimal. In one case, the patient had not been able to achieve a good recovery and would fall sick frequently with fever and diarrhoea. When this patient was healthier, he was still too weak to dig in the garden or do very much in order to generate an income. When this particular patient would fall sick, the workload of his stepmother returned to the same level as before the patient started HAART. She could not go out to her gardens and frequently had to stay up all night tending to the patient.

> The responsibility I now have is since now he is seriously sick, I am the one to prepare him some tea, wash his clothes, take care of him to swallow his medicine, support him to go to ease himself and this morning I saw since I still have to do all this for him, let me work near home.
> (caregiver 2 interview 2)

The other instance where the caregiver's responsibilities remained unreduced, was the case of a man caring for his wife who started HAART when she was found pregnant. During the course of her pregnancy, she had fallen sick with a serious case of malaria and her husband (who was interviewed as the caregiver) had to go into debt to pay her hospital bill and do most of the domestic work, such as fetching water and digging in the garden. In between the first and second interview with this family, the wife delivered her baby, which meant that husband had to continue to do the domestic work and raise additional funds for the new baby.

> Now my wife fell sick *(with malaria)* and I had to spend about 180,000 shillings to take her to the hospital.
> (caregiver 11 interview 1)
>
> I: Have your responsibilities towards her reduced now that she has given birth compared to when she was still pregnant?
>
> R: Let us say it has increased because she is still weak. I still have to do all I did when she was still pregnant, I have to still handle her like a glass, she's still fragile because she is not yet fine.
> (caregiver 11 interview 2)

These were both extreme cases of what was true of all the patients and caregivers in the study. While the patient was considerably more independent of the caregiver, the patient was still thought of by the caregiver as ill and therefore in need of special care.

Caregivers still felt responsible for the patient and paid special attention to the patient's lifestyle and wellbeing. Food for the patient remained an important issue, though its importance is much reduced from when the patient was ill. Caregivers knew that it was important for the patient to eat a variety of healthy foods. They felt eating was important for the patient in order to buffer against the power of the medication. However, the patient no longer deserved his or her own special diet. The patient now ate along side the rest of the family, however much more attention was paid to the quality and quantity of food for the entire household because the diet of the patient was so much more important.

> Will you cook beans every lunch and supper --- they advise some cabbages, avocados, fried eggs, so he eats on each of them so as to be strong and you cannot be strong when you have not eaten good food
> (caregiver 7 interview 1)
>
> Ok, about the food, we don't make special, for we have .... tried to eat good food for all of us.
> (caregiver 3 interview 1)

Caregivers also felt responsible for the patients' adherence. Again they felt that the drugs were very powerful and must be taken correctly to avoid harming the patient. Most caregivers stated that ensuring the patients' adherence to their drug regimen was not a challenge because the patient had already established a routine with their medication.

> No because I try by all means to ensure she takes the drugs on time and to remind her so she doesn't forget.
> (caregiver 13 interview 1)
>
> I see at times that when she had just started that is when I would put what effort, "it is time", but now she is settled and straight in taking her drugs,
> (caregiver 1 interview1)

Another important way that caregivers tried to keep the patient healthy was by shielding the patient from excess worry or grief. Both patients and caregivers discussed how harmful worrying could be to ones' physical wellbeing. Caregivers felt it was their duty to keep worries or arguments away from the patient. They also felt it was their responsibility to lend the patient emotional support because this could preserve the patients' physical wellbeing.

> but since she knows I am by her side I think I make her strong.
> (caregiver 10 interview 2)
>
> For me even if there is something which could cause us to quarrel, I don't say anything, I just handle it myself and -------aahh--- it passes without him knowing about it-------
> (caregiver 3 interview 2)

Continued fear for future of family. Though the reduction in worries for caregivers was immense, again this relief was not complete as there were some areas of concern left over from the period when the patient was ill. One important issue was thinking about the development plans for the family. Caregivers took this issue very seriously as they knew that their own wellbeing was dependant on the success or failure of these development plans. An important improvement in this area was that the caregiver no longer felt alone in worrying about the fate of the family after the patient had died. Now that the patient had recovered, the caregiver and patient could work on these family development plans together.

> Now since he is living and healthy I am not so worried because I know now if he decided to do some thing I can tell him; "let's do this.." and that will happen, to see that at least by the time he is not living the children are grown.
> (respondent women's caregiver focus group)

While caregivers were encouraged by the fact that the family was gaining ground financially, rather than losing ground as before, caregivers remained concerned that they would be left in a bad situation if the patient were to die. Many caregivers saw that they were in a very difficult position. They were struggling to recover from the financial consequences of the patient's illness and still not able to meet all of the present needs of the household. Several respondents expressed concern that the family was not able to save in a way that would be needed to accomplish financial security.

> Now *(the patient)* doesn't work and me also I have grown old. I don't have energy to do this or that at home. Will I think of the future being different when there is no one going to anything about changing this future for the better? .... Eh, eeh (No.)
> (caregiver 7 interview 2)
>
> Eh—It worries me that we can't build, but I have courage because we are on these drugs. Some times I worry that we have a lack of money to sustain ourselves. It also worries me because how will the children's future be if we don't prepare for them now?
> (caregiver 3 interview 1)

5.3 Issues Specific to Concordant Couples

There were strong themes which were prominent for the married couples in this study, which were not present in the other patient-caregiver relationships. In the study, there were four households where spouses were caring for each other. In all four cases, both members of the couple were HIV+ and both were taking HAART. Given this family situation, the distinction between patient and caregiver was somewhat arbitrary and artificial. The spouse who acted as the caregiver was the one who was healthiest at the time. All couples said that the health and well being of the wife was valued equally to the health and well being of the husband.

> Eeehh – me I balance, I care for myself the way I care for his life. Because if I start caring for him more than myself, I might cause a problem and if I care for myself more and neglect him, it would also be bad. Because for men, yes they are strong and have to work hard for their families, but they also need support from the family so me I provide this support
> (caregiver 3 interview 2)

In the case of spousal caregivers, the crisis period for the family developed gradually with one or both spouses having an increasing number of "suspicious" illnesses. In all four couples in this study, the testing of the husband occurred first which lead to testing for the wife and the eventual commencement of HAART for both.

Once it was confirmed that both partners were HIV+, all couples in the study had to confront the considerable mistrust and conflict provoked when one or both of the spouses started to wonder who had brought this disease into their relationship. All four of these women described feeling very hurt and angry at this time and it is at this time when all of the wives in the study discussed that they had seriously considered leaving their husbands. All of the husbands interviewed recounted events in a way that indicated that they accepted blame for bringing the virus into the relationship.

The wives interviewed all described going through a distinct process of suspicion, hurt and anger, followed by acceptance, (though not necessarily forgiveness in one case). Many women cited the fact that they were also HIV+ as the most significant factor in their decision to remain with their husbands. Having made the decision to stay in the relationship, the fates of the husband and wife were very much intertwined. Both partners needed to work as a team in order to stay healthy and care for their family.

> Yes, it is true, I am the one who infected her with the disease but I did not intend for it to be like that.
> (patient 9 interview 2)

> I was very angry and thought many words....now me, I had lived very carefully. But now see what this man is giving me AIDS. I wanted to leave him and go back home, but again I thought how?----- I decided to face my problems and stayed. It is too late for me to leave. I even had given birth to one child.
> (patient 11 interview 1)

Planning for the future of the family was a very significant issue with these couples as there was no healthy member of the family to fall back on. Also, all of the married respondents interviewed were very committed to their families' development plans. Both partners seemed well aware that they would be left in a very vulnerable position if one spouse should die before the family was able to improve their situation. Couples were also forced to reconcile their original planned family size with their new reduced financial capabilities

> we are as we were before because even educating this child we do it both of us --- he can sell bananas, I sell sorghum and beans so we both contribute to his school fees.
> (caregiver 8 interview 1)
>
> I: Before you knew that you had HIV virus, did you plan to have more children?
>
> R: Yes, I had the plan but now I think I should first look after these ones I have because if I add on more, it will become a problem to satisfy their needs .....Let me first look after these that I already have.
> (patient 3 interview 2)

Social stigma was another factor which very much bound these couples to each other. In all four cases, the husband became visibly ill, thus "broadcasting" his HIV infection to the community. As sexual partners to these HIV patients, all of the women interviewed were assumed by the community to be HIV+ even before they went for testing themselves.

CHAPTER 6: DISCUSSION

There are several findings from this study which are noteworthy as they have either not been previously mentioned in the literature or are significantly different from work previously conducted. Another finding of this study is significant because it verifies the findings of previous studies done in that field. These findings merit further comment and will be discussed in the following section.

Uncertainty

One important difference between the results of this study and pre-existing literature in this field is on the topic of uncertainty. To date, the only studies which have explored uncertainty in HAART patients have been done in a Western context. In the Western Literature on this topic, patients described being beset by uncertainty; How long will these medications work for me? How long will I live? How healthy will I be during this time? Much of the Western Literature on this subject warns that patients must be assisted to manage this uncertainty or they will slip into despair.

For the patients and caregivers in this study uncertainty was not described as an overwhelming issue at any point, but it was even less dominant after the commencement of HAART. It was as though the presence of the medication, removed much of the doubt that patients had regarding their own future. This was almost opposite to the mind-set described in Western HAART patients. Patients in this study described feeling health-related uncertainty only with respect to the continued supply of the medication. On all other issues, the faith that patients had in the drugs dominated. This allowed patients enough confidence to express certainty on many topics. Many patients testified as to this faith, saying that as long as they were under the protection of the drugs, they were “sure of their lives”. This confidence in the drugs was quite ubiquitous throughout all of the interviews, which would lend credibility as to its veracity.

It was possible that the difference between Western patients and patients in this study on the topic of uncertainty was due to the difference in exposure to medical technology. Western HAART patients are likely familiar enough with drugs and the treatment of chronic conditions to know of medicine's limitations and failings. African HAART patients likely do not have this level of familiarity. This was seen most clearly in the fact that none of the patients interviewed in this study were aware of the possibility that these drugs may become less effective for them over time. This is an issue that should perhaps be better addressed in medication counselling, given that many patients will likely live long enough to see their medication become less effective, thus causing some disillusionment or misconceptions about the power of this medication.

Dying a "Good Death"

One of the most dramatic changes that HAART brought about in patients and caregivers, was a reduction in fear around the conditions of the patient's death. First and foremost, respondents were confident that patients on HAART would die a much better death compared to other AIDS sufferers. It is likely that patients and caregivers are describing a belief that is not only held by themselves, but by the community at large. This belief was also repeated to the primary investigator by other individuals who were not being interviewed for this study. Patients and caregivers are quite relieved by the belief that when the patients die, their suffering will be dramatically reduced in intensity and duration. Before HAART, patients said they felt tremendous fear that they would die in an undignified way, with great suffering and perhaps alone. Caregivers also described that before HAART, they felt very afraid to see their loved one suffer the pain and indignity of an AIDS death. The commencement of HAART seemed to completely erase all of these fears. Patients and caregivers were no longer afraid of the patients' physical suffering. Patients were also relieved that they would not die alone, with the stigma and shame associated with an HIV death. The fact that these themes emerged so strongly from both the patient and caregiver interviews shows how much shame and suffering was witnessed when a member of the community died of AIDS in the pre-HAART era.

This theme has not been previously discussed in any of the literature reviewed for this study. It is perhaps an unexpected benefit that HAART can not only provide a psychological benefit by allowing patients an extended and higher quality life, but many also have benefit in a palliative sense; relieving the very human and understandable fears of dying in pain and alone.

Stigma

While there are no published studies which discuss the affect of HAART on beliefs around death and dying, several studies have been done in sub-Saharan Africa on the effect of HAART on patients' experience of stigma (Brandt, Dawes & Bray, 2006; Chenard, 2007 in Ncama et al., 2008; Skogmar et al., 2006). These studies suggested that the way patients' experience social stigma is largely unchanged by HAART and that HIV stigma is still a significant problem for patients. These studies also suggested that patients acted strategically when disclosing their HIV status to others; patients made decisions motivated by the hopes of gaining additional social support while at the same time, minimizing exposure to stigmatization. The findings of this study are somewhat at odds with these previous studies.

While patients and caregivers in this study expressed a wide range of openness regarding the patient's HIV status, they were quite uniform regarding their willingness to disclose the patient's HIV status if it would be of benefit to another HIV infected person. Many patients and caregivers said that they felt obligated to use the knowledge that they had gained from their own personal experience in order to help others in their community access HAART. Previous articles on this topic have not mentioned that patients felt an obligation to disclose their sero-status in an altruistic way, in a way that would help others access this life saving medication.

The behaviours and comments of the respondents regarding HIV stigma and status disclosure, betrayed somewhat of an ambivalent attitude on this topic. It was obvious that HIV stigma was still significant in this community. However, it was clear from respondents' sometimes contradictory responses that the nature of HIV stigma was changing in the community at the same time as the respondents' personal vulnerability to HIV stigma was also changing. Respondents seemed to know that they "should" tell the Research Assistant that they were very open about the patients' HIV status, but they often made contradictory comments, indicating that they did not always do what they felt they "should". This demonstrates that matters of stigma and disclosure posed patients and caregivers some social difficulty. The fact that HIV stigma was still a serious concern for patients was consistent with previous studies on this topic.

Many patients in this study described experiencing a boost to their self-esteem through taking HAART and recovering physically. Many patients stated that they felt proud of themselves now that they now looked good and could do their work as a normal person. Caregivers reported feeling proud that others could see how well they had performed in their role as caregiver to the patient. If stigma can be said to harm patients by leading them to internalize negative stereotypes; most HAART patients and caregivers in this study have become less stigmatized as a result of taking these drugs. Patients often described feeling equal to others and very many patients said that they felt even "better off" than other members of their community who were not under the protection of this powerful medication. Patients also described feeling less vulnerable to stigma because they no longer fit the AIDS stereotype.

While most patients still reported being reserved about their HIV status, the majority of patients also described reintegrating well into their communities. Perhaps this is because of their renewed self esteem and reduced vulnerability to stigma.

These findings lend support to advocates of grassroots organizations that attempt to show the benefit of "Living Positively". While the cause and effect cannot be known as result of this study, clearly these organizations are either building on an idea which already exists in the community, or have been successful in helping HAART patients improve their self esteem enough to consider themselves role models for their community.

Diversity in Caregivers

Given that there is such a dearth of literature on HIV caregivers in sub-Saharan Africa, there are many findings in this research that are unique. One important finding was quite unintended. The unexpectedly large diversity found amongst the caregiver sample was a challenge during sampling and data analysis portions of this study; however the large amount of diversity in the caregiver sample could be considered a valuable finding in itself. This study was able to illuminate some of the important factors which need to be considered when analyzing caregivers' experiences. Some of the important factors which produced variation amongst the caregivers were; the caregiver's relationship to the patient, the level of independence the patient is able to achieve at the time of care giving, the duration of care giving and the reason that that caregiver has stepped into fill this role.

This study found that patients were often cared for by not one, but a series of primary caregivers. Often the caregiver who was interviewed for this study had stepped in to fill a void left when another family member stopped acting in this role. By talking to both the patient and the caregiver about their entire HIV narratives, a more complete history of the household narrative was taken. This often included which family members cared for the patient at different times and why there was a change in the primary caregiver. The change in caregivers occurred for many different reasons. Often this happened because of a change in the health status of the patient. In other instances, the caregiver changed because the previous caregiver had died, or because the previous caregiver left the patient because of fear of social stigma. In all but one case, care giving obligations did not disappear after the patient physically recovered, but were simply reduced. Changes in the patient's primary caregiver happened both as result of the patient becoming more ill, and as a result of the patient improving.

By gaining a more complete understanding of the families' HIV narrative, the significance of family instability in the lives of patients and caregivers was emphasized. In a way, it is this family instability that "decided" whom would care for the patient. The fact there is frequent change, suggests caregivers and their families are in crisis mode; they are coping in any way that they can and will happily stop coping in this way if there is an opportunity. Noting the large amount of instability that these families experience, makes plain the fact that HIV infection does overwhelm families, and that HAART greatly reduces, but does not eliminate the tremendous social, emotional and financial burden that HIV has caused. Previous studies that have been done on family instability related to HIV (Hosegood et al., 2007; Madhaven & Schatz, 2007) discuss this issue at a household level without considering the impact of these frequent, emotional changes at the individual level.

Caregiver Burden

One source of diversity amongst the experiences of caregivers was due to the fact that caregivers became overwhelmed by their situation and felt the need to separate themselves from the patient. The overwhelming nature of HIV care giving has been previously discussed in the literature and the stories told by caregivers in this study are consistent with these findings.

One of the themes common to many of the stories told by the caregivers in this study was that caring for the sick patient was put at the top of their list of priorities, while caring for themselves was one of the lowest priorities. Caregivers in this study also described neglecting their work in the family garden when they could not complete all of the tasks required by the household. These findings are supported by Urduang (2006) who discusses the important role of gender and self sacrifice in HIV care giving work in Africa. Rajaraman et al. (2006) also demonstrated similar findings in their study which found that household income is often lost because the labour of the caregivers must be devoted to the patient.

When asked if they felt supported in their role as HIV caregiver, caregivers in this study were divided on this subject. Some caregivers stated that select friends and neighbours would try to help them and some stated that there was no one to assist them in this time. However all caregivers stated that they felt there were some members of their community who were passing judgement both on their family and on their own personal fulfillment of their care giving role. Feeling lonely and isolated with worries was very common to all caregivers while the patient was sick. These findings are supported by studies done by Orner (2006) who found that caregivers often felt lonely and by Mwinituo and Mill (2006) who found that HIV caregivers experience stigma and often isolate themselves as a result.

Orner (2006) found that caregivers often bore the brunt of emotional strain in the home. MacNeil (1996) and Orner (2006) both discussed that caregivers persisted in their work because they felt family obligation made all of this work their responsibility. These themes also emerged from the respondents in this study. Many caregivers reported trying to keep tension away from the patient in order to protect his or her health. Several caregivers stated that the nature of their familial connection to the patient left them no choice regarding whether or not to assume their care giving responsibilities.

It is also important to note that in this study, most of the caregivers felt that their responsibility for the patient, while diminished in workload, remained after the patient had recovered after HAART. This indicates that concern regarding caregiver burden and caregiver wellbeing cannot be forgotten in this post HAART era.

CHAPTER 7: CONCLUSIONS

7.1 Limitations of Study

Many of the limitations of this study are inherent to the nature of the study and are discussed in the methodological basis section of the study. However the following points will be discussed in greater detail in the following section as they provide important information on the context of the study which is essential for a full consideration of the results.

Several of the limitations faced by this study presented themselves because of the large socio-cultural differences that existed between the research participants and the primary investigator of the research project. Examining these differences between researcher and participant is essential in order to uncover how preconceived ideas on both sides can influence the results of the research (Mallory, 2001).

It was evident in the interview process, respondents had already formed two very strong ideas about the research team that were difficult to overcome and had an effect on the results of the study. The first of these was often referred to by members of the research team as the "mzungu effect". It often happened that respondents saw interaction with the research team as an opportunity to gain financial assistance; therefore respondents would overemphasize their poverty in the hopes of gaining financial assistance from the team. The following comments are examples of statements made either during the formal interview or in the question period after the interview which demonstrated this type of thinking.

> I have this question that you people, okay, you are looking after your patients in supplying them with medication, do you have any other help to give them like food or things to drink?
> (caregiver 1nterview 1)

> Now like us AIDS patients, can we receive any assistance in form of money?--- Like for us people with the HI virus if they can think about us and give us some money, we can be able to get what we need
> (caregiver 11 interview 1)

Two actions taken by the research team, attempted to mitigate the impact of the "mzungu effect". Firstly, the primary investigator attended very few of the interviews as the presence of a white researcher lead to a worsening of this problem. Secondly there was much discussion by the research team about respondents who seemed disingenuous about his or her level of poverty. When this was thought to be an issue, attention was paid to this fact in subsequent interviews and in the analysis of those interviews. Ultimately the effect of respondents being disingenuous about their level of poverty on this study is minimal as all of the respondents were subsistence farmers and obviously struggled to meet their basic needs.

It also happened that respondents often viewed the research team as being synonymous with the CB-ARV project. During the Informed Consent process, respondents were told at least twice that the research team was separate from the CB-ARV project and that their responses would remain confidential, never to impact the patient's medication supply. This idea however persisted and may have influenced the participants' responses during the interviews. This is demonstrated by the following comments.

> let me say thank you *(to the research assistant)* for the help you are putting to see that you are coming to see patients and to see that also the drugs you are sending please continue and God is blessing you
> (caregiver 1 interview 1)

The belief that the research team was synonymous with the CB-ARV project may have influenced respondents to answer questions in ways that would be perceived as being socially desirable. Respondents may have wished to portray themselves as model patients. This often happened when the research team asked patients about their abilities to comply with the teaching from the clinic about their lifestyle. This problem seemed especially pronounced in the Female Patient Focus Group Discussion. This may have been because patients also wanted to portray themselves in a positive light to the other members of the focus group as well as the research team. Interestingly, this problem seemed much less pronounced in the Male Patient Focus Group and the Female Caregiver Focus Group Discussions.

Another belief held by the respondents that may have acted as a kind of bias was the belief in a very strong connection between mental and physical health.

Respondents believed that negative thoughts could harm them physically. Patients and caregivers may have avoided discussion of their worries or negative thoughts in order to avoid ruminating on these issues, there by protecting their health. This may cause positive psychosocial changes associated with HAART to be overrepresented compared to negative changes or outstanding concerns.

> It is important that one with HIV virus should not worry themselves at all because these thoughts or worries can kill you, you can develop pressure and one day, it can strike you and you die.
> (caregiver 11 interview 1)

Another limitation of the study was that the primary investigator was working outside of her own cultural and linguistic context. This resulted in the primary investigator interpreting the results of the study with information which was relayed to her by others. The primary investigator had to rely on research assistants to describe the setting and the non-verbal communication of the interview, and the transcripts for the verbal content of the interviews. Also data analysis may have been limited by the fact that the primary investigator had only three months to gain an understanding of the cultural context of the participants. The attempts that were made to overcome this limitation were several. The primary investigator debriefed with research assistants after every interview in hopes of gaining a fuller understanding of the events of the interview. Accuracy in the transcripts was ensured with a thorough review of their quality. In order to ensure a more accurate cultural interpretation, the primary investigator discussed her ideas regarding emerging concepts at length with the research team and other the members of the CB-ARV staff in Fort Portal and Rwimi.

Lastly, the generalizability of the results of this study is limited by the sample size and the very nature of the social constructivist methodology of the study. Admittedly the results of this study are a product of this particular setting and the primary researcher's thought process. The goal of the study was to gain a depth of understanding regarding a limited number of participants as opposed to achieving breadth regarding the sample size.

7.2 Significance

An important focus of the WHO "Three by Five Initiative" was not only to improve access to antiretroviral therapy, but also to expand the amount of research being conducted regarding the provision and evaluation of ART programs (UNAIDS, 2006, p176). While the challenges inherent to studying the impact of HAART as a purely medical intervention are many, the challenges inherent to studying HAART as economic, psychological and social intervention are much greater. Despite these challenges, research in these areas is essential, because it is only through these types of studies that researchers can know if HAART is having the desired impact. The desired impact of this medication is not merely to keep patients alive, but to improve the day to day lives of all people affected by AIDS.

In sub-Saharan Africa, researchers and health systems often neglect mental health needs in the face of such daunting physical health problems (Brandt et al., 2006). However at Alma Ata (International Conference on Primary Health Care, 1978), the International Community agreed that health is not just the absence of disease, but a state of physical, mental and social wellbeing. Furthermore, it was agreed that this state of health is a universal human right. It is time that this right is also extended to HIV infected Africans.

As the ARV Rollout continues to expand across sub-Saharan Africa, it becomes more and more essential for those who work with and advocate for HIV affected communities to consider the ramifications of treating HIV as a chronic health condition as well as an acute infectious disease (Russell et al., 2007). What must accompany this shift in thinking is a consideration of the unique mental health needs of those who are living with a disease which is at the same time; debilitating, stigmatized, fatal and infectious (Remien & Mellins, 2007). It must also be recognized that patients' illnesses affect more than just themselves and that family members of these patients are also in need of long term support.

This study has been able to show that HAART is successful in dramatically improving the mental wellbeing of patients and caregivers, thus bringing some relief during a time of incredible crisis. Patients and caregivers in this study described experiencing, a great renewal of hope and a huge reduction in levels of stress and social isolation. Patients were able to feel pride at their ability to become productive members of their households and caregivers were able to return to their normal activities.

However, this study has also shown that patients and caregivers still faced many challenges after the commencement of HAART. The challenges of the "post-HAART era" were no longer acute and overwhelming as they were during the previous period of crisis, but perhaps were more insidious because these challenges appeared to be without end. Chief amongst the concerns of caregivers and patients were financial problems. Families were financially devastated by their patients' illness. In the "post-HAART era", families continued to be disadvantaged in their ability to get out of debt and regain assets by their patients' continued delicate condition. Socially, patients and caregivers were also forced to negotiate the complex issues of stigma and status disclosure in a social environment which was definitely in flux and not always supportive. Psychologically, patients and caregivers had to carry on, burdened by the grief and pain of broken families as well as the great fear that their medication supply could be interrupted and they could be launched back into a state of crisis.

Studies such as this one add to the growing call that HAART patients and their families' require more than this life saving medication in order to rebuild their lives (Russell et al. 2007; Orner, 2006; Bernays, Rhodes & Barnett, 2007). Patients and families need economic, social and psychological support after the incredibly destabilizing experience from which they have emerged. It is insufficient to keep patients alive without attending to their broader health needs. According to the concerns expressed by patients and caregivers in this study, there are three specific areas which require attention if HAART programs are to truly practice community based, primary health care.

1) Financial assistance and/or microcredit programs should be incorporated into HAART programs in order to acknowledge and address the financially devastating nature of HIV illness.
2) International governments and funding agencies must continue to address issues related to the sustainability of the antiretroviral drug supply. This is

especially important as the World Trade Organization's "Agreement on Trade Related Aspects of International Property Rights" (TRIPS Agreement) transition period for developing countries expires. The coming years bring increasing challenges to those companies providing generic, low cost versions of antiretroviral drugs (AVERT, 2008). Confidence in the security of the antiretroviral drug supply is essential for the psychological wellbeing of the millions of HAART patients in developing countries who are aware that their lives depend on this medication. A secure drug supply is also essential for the crucially important issue of drug resistance.

3) Counseling must be offered on an ongoing basis to patients and their families in order the help them live positively with HIV and HAART. Also post test clubs who are also serving this purpose should be supported as much as possible.

While of course it is easy to make the argument that the above actions are unrealistic given the massive amounts of national and international effort that has been needed to get the ARV rollout to this point. However, the argument must also be made that the implementation of the above actions would be simple and inexpensive compared cost and complexity of the ARV Rollout itself. If the call is not made for mental health issues to be given greater standing amongst the health needs of those affected by the HIV pandemic, it is certain that they will never be addressed.

7.3 Dissemination of Study Results

The results of this study will be disseminated in Uganda through several research partnerships that are presently in place between the University of Alberta's School of Public Health, Makerere University's School of Public Health and the Kabarole Health District. As this study will serve as one of many evaluation tools for the Community Based Antiretroviral Treatment for AIDS Patients Project, the results of this study will also be made known to the researchers of this project. Every effort will be made to disseminate the results of this study in Canada through means of presentations and publications in scholarly journals.

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Appendix A

Sample Patient Interview Guide

Just to get to know you a little better can you tell me a little about who you live with here? How are they related to you?

What is your occupation?

Can you tell me a story that would help us to understand how things were for you before you started taking ARV's? What kind of things were you thinking and feeling?

Can you tell us how you felt when you came to know that you were HIV positive?

Was it a surprise to you to find out you were positive?

Was there any part of you that felt relieved to know what was wrong with you so that you could start doing something about it? (ie. Taking medications)

Can you tell me about how you are thinking and feeling now that you are taking ARV's?

Do you think that your life has gone back to ("normal") being the same as it was before you became sick or is it different in some ways?

- In what ways is your life different?
- Are your priorities for life different now than they were before?
- Is life different for you now because other people treat you differently?
- How do others treat you now?

Do you think that what you have gone through with HIV has changed your thinking in anyway?

Can you tell me what have been some of the most important changes that have happened in your life since you started taking ARV's?

- Why has this change been so important?
- Can you give me an example of this change?
- Why are these changes important?

Did you feel hopeful about the future before you started taking ARV's?

-Why or why not?

Has there been a change in how hopeful you feel about the future now that you are on ARV's?
-Why has this change happened?

- How do you think this feeling affects how you conduct your life?

When you first started doing your work again after you regained some strength were you very scared of pushing yourself too hard?

Do you feel as healthy and strong as any other person in your community?

How is your health or strength different from other people's?

What kind of things did you used to worry about before you started taking ARV's?

What kind of things do you worry about now?

- Do you think you have fewer worries now?
- How much do these worries affect your life?

- Do you worry about how long the supply of free medication will last?
- Is there anything about these medications that scares you?
- Do you ever have transportation problems related to your sickness or taking ARV's?

Are there any new problems that you face now because you are taking ARV's?

-What are these problems?

-How do they affect you?

-Why are they important?

Are there any new expenses that you face because you are taking ARV's?

- What does that mean for you and the people that you live with?

Can you tell me if you or your family experienced money problems when you were sick?

Has it been easy to recover from this financial hardship?

Are you still having problems to recover from this hardship?

What does this mean for you and the people that you live with?

I understand that when a person starts ARV's, they are often taught that they should try to live in a healthy way. Are you able to do all of the things that they taught you about at the clinic?

- What kind of things did they teach you about? (bednet? Boiling water? Avoiding alcohol? Not working too hard?)

- Are you able to do all o the things that they taught you?

-(If no) How does that make you feel?
-Is it hard to afford to the healthy food that you need to take ARV's?

-Does this make problems of distributing food in your house?

- How do you feel when you have to make hard choices about who will get the best food?

Is it important for those with HIV not to worry ?

Why is it important?

Do worries disturb you or are you able to control them?

Do you ever hear contradicting advice from you're the clinic staff and others (friends/family/ church group/ traditional healers) about how you should care for yourself?

How does that make you feel?

Do you ever think that you would like to stop taking these drugs?

Why?

Do you feel like you have all of the knowledge about ARV's and HIV that you need to manage your health?

Has the teaching that you received at the Rwimi Clinic been very helpful to you?
Why?

Do you feel like the improvement in your health is fragile? Like it could disappear at anytime or do you feel that it is secure and you can rely upon your health?

- (if the response is fragile) Does this frustrate you?
- (if the response is fragile) Does this affect how you conduct your life? How?

How do you think being on ARV's has changed how long you will live?

-How many additional years do you think that these drugs will add onto your life?

********-Why do you think this?

Do you have a plan about what kinds of things you would like to accomplish before you die?

- Are you doing anything now to act on this plan?

*******-Are you able to do all of these things? *******

*****- (if no) Does that make you feel scared or frustrated?****

-Which people do you want to benefit by these actions?

- (if not mentioned) Do you think about how you will leave your family after you die?

-What kind of things do think you need to do in order to leave your family well when you die?

How has being on ARV's changed your interest in being around other people?

-Who do you choose to spend time with now?

-Why do you choose these people?

- Do you sometimes feel like people cannot understand what you have gone through to be here today? (if yes, does that make you feel lonely sometimes?)

-How did you feel about being around people before, when you were sick?

- Did you feel lonely when you were sick?

- Was this because you were not around any people or was this because you felt people couldn't relate to your experience?

-Do you feel you are better able to help others now?

-Is this important to you?

- Can you tell me about a time when you were able to help someone else?

-Do you feel more grateful for the help of others?

- Do you participate in any kind of group socializing that you did not do before (going to church more, playing on a football team, joining a cooperative, drinking with your friends?)

Do you have any friends that are also on ARV's?

-How is your friendship with them different from your friendship with others?

- How did you meet these friends?

-Where and when do you spend time with them?

-What kinds of things do you talk about?

Do you know of people who have died of HIV because they did not get these drugs?

Do you know of people who are HIV positive who are not taking these drugs?

<u>**Do you know of anyone who refuses to go and test because they are too afraid?**</u>

<u>**Do you think you have more courage than that person because you made a choice to live with HIV and they have chosen to die rather than know their status?**</u>

<u>How does that make you feel?</u>

Can you tell me about how you experience HIV stigma in your community?

What do you think that others in the community think about people who are in treatment for HIV?

Do you find that you often have to explain to people your illness (before ARV's) to others or do they already know what you have gone through?

-How did they come to know about your sickness?

If you do have to explain your illness (before you started on ARV's) to others, what do you choose to tell them?

-Why do you tell them this?

Do you think that being on drugs makes it easier to tell people that you are HIV positive?

(if yes) Why do you think these drugs give you courage to tell others about your status?

Is there a difference in telling people who you are very close with and people who you are not so close with?

(If the person is open about their status) How did you find the courage to be truthful with people about your status?

(if the patient is open about their status) Do you think that being open about your status benefits you or does it only benefit others?

How does it benefit you?

How does it benefit others?

How do you feel that you are able to benefit others?

These medications often help people because they no longer look as though they have HIV. (for example, ARV patients are not too thin, don't have mouth sores or skin infections) Why is that important?

<u>How do you decide who you will tell about your HIV status and who you will not tell about your HIV status?</u>

<u>Do you think that looking healthy gives you a choice about who you will tell and who you will not tell about your status?</u>

<u>Is this important to you?</u>

<u>Why is this important</u>?

Do you go out in the community more now than before?

- Is it hard sometimes?
- Do you feel ARV's can help you to live positively?

Can you tell me about how you felt when you first started going out in the community again?

- How did you cope with this?

- Was it very hard for you? Why?

What do you think other people thought about you when you were sick?

How do you think your sickness affected the people that you live with?

- How did that make you feel?
- Have things changed for the people that you live with now that you are on ARV's? How have they changed?

Can you tell me how independent you feel now?

- How do you think this affects your pride/dignity?

- What kinds of things do you do now that you feel more independent?

Do you think your relationship with your children has changed since you started the medication?
- How do you think it has changed? Do you think it is a change for the better or worse?

- Is there any wisdom or life lessons that you think it is important for you to share with your child?

- Are you able to share these things with them?

- Do you feel you are able to care for your children better now that you are well?

- Do you have time/energy to sit and tell stories with your family now?

How do you think being on ARV's has affected your relationship with your Partner?

- Is there more or less tension and fighting now?

- Is there ever physical fighting or abuse in your house? Has being on ARV's changed how often this happens?

- Do you feel closer to your partner? Why/why not? Can you tell me about an example which shows this?

- Has being on ARV's made any new problems between you and your partner?

- Do you have more sexual feelings since you have started taking ARV's?

Is your faith in God important to you?

Sometimes when people are really struggling, they can lose faith in their God. Did this ever happen to you when you were sick?

Has being on ARV's changed how you feel about your God?

Some people say that those who die of HIV die a death with a lot of suffering. Have you heard from others or seen anything your self that confirms this?

Did this scare you before you started taking ARV's?

Have your heard or seen anything from others that would make you think that those who take ARV's die a different kind of death?

- Has that changed how you feel about what will happen when you die?

When you were sick did you feel that death was very close at hand for you?

Did you think about death a lot?

Do you still feel that death is close at hand for you?

(if the answer is no) Does this make you feel relieved, can you describe this relief to us?

Even though you feel healthy and strong and don't look as though you have HIV, you still have to live knowing that you have this virus in your blood. How does that make your life different from other people's lives?

When you were sick is there anything that you wished you had done differently?

Do you still have these regrets now that you are on ARV's?
Why?

What advice would you give to others who are starting on this journey?

Sample Caregiver Interview Guide

Just to get to know you a little better can you tell me a little about who you live with? How are they related to you?

What is your occupation?

Can you tell me a story that would help us to understand how things were for you before "X" started taking ARV's?

Can you tell us about how you came to know that "X" was HIV positive?

What it a surprise to learn that "X" was HIV positive or did you suspect before?

Did you feel any relief to finally know what was wrong with "X"?

Can you tell me about how you are thinking and feeling now that "X" is taking ARV's?

Do you think that your life has gone back to ("normal") being the same as it was before "X" became sick or is it still different in some ways?

- In what ways is your life different?
- Is it different because this experience has changed you? How have you changed?
- Are your priorities for life different now than they were before?

Can you tell me what have been some of the most important changes that have happened in your life since "X" started taking ARV's?

- Why has this change been so important?
- Can you give me an example of this change?
- Why are these changes important?

Can you describe what kinds of feelings you were having before X started taking ARV's?

-Did you feel a lot of stress?

- How did this stress affect you?

-What kinds of things caused you worry?

Did you feel that death was close at hand for X?

Did you spend a lot of time thinking about death?

Do you spend less time thinking about death now?

- (if yes)Can you describe the relief that you feel now that death is not so close for your household?

What other kinds of emotional feelings do you have now? (happy, relieved, free, worried?)

How did you feel about the future before X started taking ARV's?

Did you have fear when you thought about the future?

What kinds of things caused you to feel afraid?

How do you feel about the future now?

- Do you feel more hopeful, less afraid?

Has X taking ARV's made any new worries for you that you did not have before?

- What kinds of things do you worry about?
- Why do these things matter to you?
- Do you worry about how long the supply of free medication will last?

- Is there anything about these medications that scares you?

At the Rwimi Clinic, they sometimes teach people about how to live well while taking ARVs. What do you know about what someone can do to live well when they are on ARVs?

Do you ever worry that the patient is not able to follow all of this teaching?

- Do you worry about X taking her/his medication properly?
- Do you worry about X having enough healthy food to take ARV's properly?
- Does that create stress when food is divided up in your household?
- What do you feel when you have to make hard choices about who gets the best food?
-

Sometimes at the Rwimi Clinic they tell patients that it is important not to worry too much. Sometimes they also teach family members that they should live in peace with the patient and not annoy them. Does it ever happen that you are worried about things but you do not share these worries so that you don't upset or annoy the patient?

How does that make you feel?

Do you share these worries with anyone?

Is your faith in God important to you?

Sometimes people who have many worries can start to feel like their God has abandoned them. Did this ever happen to you?

Has there been any change in your faith in God now that "X"s health has improved?

Do you feel that the improvement in "X"s health is fragile or do you feel that it is secure?

- (if the response is fragile) Does this frustrate you?
- (if the response is fragile) Does this affect how you conduct your life? How?

Are there any new expenses that you face because "X" is taking ARV's?

- What does that mean for you and the people that you live with?

Can you tell me if your family experienced a lot of problems with money when "X" was sick? Can you tell me about these problems?

Have you recovered from these money problems?

What do these problems mean for you family?

How is "X" able to help your family recover?

Can "X" do everything that you would like him/her to be able to do to help you recover?

It often happens to people who are caring for those who are sick that they have more responsibilities than one person can manage. Did this happen to you?

-Did you feel guilt because you were unable to do all of the work?

- Which things would you chose to do if you could not do everything?

-Why did you choose those things?

-Which things caused you to feel the most guilt if you had to neglect these things?

-Why did these things cause you such guilt?

Do you think that your responsibilities to the patient are reduced now?

Do you feel a sense of relief if your responsibilities are reduced?

What kinds of things do you still have to do for the patient?

- Do you still have to forgo other responsibilities on order to help your patient?

-What are you major responsibilities in the house?

-- Are there things that you can pay more attention to now that you have more time to do other things?

- Which things do you spend time on?

-Why are these things important to you?

Do you think that you have the same responsibilities as any other mother/sister/wife/husband now or do you still have more responsibilities?

<u>It seems that when people care for those who are sick with HIV, they treat that person more delicately than other patients who are sick with other diseases. Do you think this is true?</u>

<u>Why?</u>

Are there things that you are able to do now that you did not have time to do before because you were too busy with your care giving work?

-What kinds of things do you do now?

- Are there any things that you like to do for yourself that you could not do before?

-Does this help you to feel more relaxed?

Can you tell me if your physical health has changed since X started taking ARV's?

-What kind of changes have you noticed?

Sometimes caregivers are so worried about the condition of their patient that they do not care for themselves as well as they should. Did this happen when "X" was sick?
-Would you feed him or her better/more food than you would eat?

-Did you have to work very long days?

Do you still put the health of your patient before your own?

-Do you let him or her eat first?

-Do you do more work around the house because the patient has to rest?

Did you ever feel lonely before X started taking ARV's?

-Were you lonely because you could not go and visit people?

-Did people come to visit you?

-Did they offer to help you?

-Did you feel lonely because people could not understand what you were going through?

Do you want to spend time around other people more now that X is taking ARV's?

- Do you spend more time around other people now?
- Does this help you to feel better? How does this help you feel better?
- Who do you spend more time with? (church, sports teams, visiting friends and family, joining a collective, drinking with friends?)
- Why do you choose these people?

Do you ever talk with other people who also care for those who are on ARVs?

How is talking to these people different than talking with those who do not do this work?

What kind of things do you talk about?

Does having these friends give you courage to be strong against those people who stigmatize those who are affected by HIV?

What do you think other people in the community think about people who are taking ARV's?

-How does this make you feel?

What do people in your community know about why "X" was sick before?

-How did they come to know this?

How does this affect what people think about you in your community?

Do you often have to explain to others why "X" was so sick, but is now well?

- If you have to explain this to others, what do you choose to tell them?

-Why do you tell them this?

- Do you tell different people different things?
- Why?

Do you find it hard to tell people the truth about "X" sickness?

Why?

Do you find it easier to tell people now that you are doing something about "X's" illness?
Why?

These medications often help people because they no longer look as though they have HIV. (for example, ARV patients are not too thin, don't have mouth sores or skin infections)
Why is that important?

Why is that important to their caregivers?

How do you decide who you will tell about your patient's HIV status and who you will not tell about your HIV status?

Do you think that because the patient looks healthy this gives you a choice about who you will tell and who you will not tell about his/her status?

Is this important to you?

Why is this important?

Do feel that there has been a change in how much support you feel from people in the community now that X is taking ARV's?

- Is there more support now?
- Who do you feel the most support from?
- Do some people who still believe in HIV stigma treat you badly because they now know that "X" has HIV?

Do you think X being on ARV's has changed how well you are able to look after your children?

- Why has this happened?
- What kinds of things are you able to do better than before?

How many additional years do you think ARV's will give X?

-Why do you think this?

Will you be left with the responsibilities of the household once X dies?

- Did that make you feel very afraid when "X" was sick?
- Why?
- Do you feel less afraid of this happening now that "X" is taking ARVs?
- Why?

Is there anything that you would like done that will make things better for you once X has passed away?

- What things would you like to be done?
- Why are these things important to you (your family)?
- Do you worry that these things cannot be accomplished?
- Does this make you feel scared or frustrated?

Do you think that your relationship with X has changed since he/she started taking ARV's?

- How has it changed?
- Do you feel more or less close?
- Is there more stress and tension now?
- Can you tell me a story that shows this?
- Is there ever any physical violence or abuse in your household? Has this changed since X started taking ARV's?
- Why do you think that this has happened?

***** (only if caregiver is sexual partner of patient)******
Have you noticed any change in sexual feelings since X started taking ARV's?

- How do you feel about this?
- Do you talk about this?
- Does this make any new problems for you?

Have you ever thought to test for HIV?

- Do you think seeing what "X" has gone through has affected your thoughts about testing?

Some people say that those with HIV can die a bad death, meaning that they suffer a lot before they die. <u>This often makes things for their caregivers very difficult</u>. When X was sick, was this something that you thought about often?

- Can you tell us what kind of feelings that made you have?
- What did you think that would mean for the patient?
- <u>What did you think that would mean for you?</u>

Is there anything that you have seen or heard that would make you think that "X" will have a different death now that he/she is on ARVs?

- What have you seen or heard?
- How does that make you feel for the patient?
- How does that make you feel for yourself?

Do you think going through X's illness and recovery with them has helped you to learn any valuable life lessons?

In this journey that you have been on through "X's" sickness, is there anything that you wished you had done differently?

What advice would you give to someone whose loved one is also on this journey with HIV?

Sample Adolescent Caregiver Interview Guide

Can you tell me about all of the people that you live with?

Have you always lived with all of these people?

- When did these changes happen?

Are you going to school right now?

- Which school do you go to?
- What level of schooling are you at?
- Has there been any disruption in your schooling lately?
- (if yes)Why was your schooling distrupted?

Do you know what illness made your X sick before he/she started taking these medications?

Can you tell me what kinds of work you had to do in your house when X was sick?

Did you find that you had a lot of work to do?

Did you ever feel very tired because you had to do so much work?

Did you ever have to look after other people in the house or only your X?

Did you ever think that it was impossible for you to do all of that work?

- How did that make you feel?

Did you feel scared when your X was sick?

- Why did you feel scared?

Did you feel lonely when your X was sick?

- Did you get to spend time with your friends when he/she was sick?
- What do you like to do with your friends?

Would any one ever come to help you with all of this work?
-How did that make you feel?

Were you worried about many things when your X was sick?

- What kinds of things would you worry about?
- Did you worry so much that you could not sleep?
- Could not study/play with your friends/eat?

Were you ever scared that your X could die?

- Can you tell me why that scared you so much?

When you were with your friends when your X was sick, could you have fun or were you too busy thinking about what was happening at home?

Do any of your friends know why your X was sick?

What do they say to you about your X having HIV?

Do many children at school know that your X has HIV?

Are all of the children who know nice to you or are some not nice to you?

-How does that make you feel?

Can you tell me about some of the changes that have happened in your house since your X started taking these medications?

Has your X started to feel better since he/she has started on these medications?

How does that make you feel?

Do you have to do less work in your house now that your X is taking these medications?

- What kind of work do you no longer have to do?

- What kind of work do you still have to do?

Do you have more free time now?

What kinds of things do you like to do with your free time?

Why do you choose these things?

Does it make you feel less scared now that you have less work to do?

- Why?

Do you feel more safe now that your X is more healthy?

- Why?

What kinds of things do you dream about doing in the future?

Do you feel like you will be more able to achieve these things now that X is taking ARV's?

Why do you think this?

Can you explain to me why this is important to you?

*************if the child is/was in school*****************

Were there some days when you would not go to school because you had to stay home and look after X?

If you would go to school when X was sick, could you concentrate on your studies?

Did your teachers at school know what was going on at your house?

- What would they do?
- How did that make you feel?

************* if the child was not in school******************

How did you feel that you were not able to go to school?

Did you/Do you hope to get back to school?

- Why do you hope to go back to school?

Can you spend more time with your friends now that your X is taking ARV's?
Do you have more fun now than you did before?

Is there anything else that you do now that involves being around other people?
(going to church more, sports teams, cooperatives?)

Is there anything that you would like your X to help you with or teach you before he or she dies?
Can you explain to me why this is important to you?

Are these the same things that your X wants to teach you or advice you about?

Do you think that ARV's will help your X live longer than he/she would have before?
-Why do you think this?

If your X was to die, would you be left with a lot of responsibility in your house?

- (if yes)How does this make you feel?
- How has this feeling changed since X started taking ARV's?

Are you and your X trying to do anything now that will make this better for you?

-How is that going?

What do you think other people in the community think about people who are taking ARV's?

-How does this make you feel?

Do a lot of other people in the village know why your X was sick?

- How do you think that they know?
- How do they treat you?
- How does that make you feel?

Do people ever ask you why your X was so sick, but has now improved?

- What do you say to people if they ask you that?

-Why do you tell them this?

Where people in the village very nice to you when your X was sick?

- Are they more nice to you now?
- Are they less nice?
- Why do you think that is?
- Who do you feel the most (or least) support from?

Did you ever quarrel or have a bad relationship with your X when he or she was sick?

- How did that make you feel?
- Why would you quarrel?
- Is there more or less fighting now? Why?
- Can you tell me a story that shows this?
- Is there ever any physical violence or abuse in your household? Has this changed since X started taking ARV's?

Have you ever tested for HIV?

Do you think you learned any useful things about life when your X was more ill?

How do you think that knowledge will help you in the future?

Appendix B

Form for the Collection of Field Notes

Date of Interview: ____________
ID Number of Interviewee: ______________________
Direction to Home:
____
____

Notes on Interview:

How were you received by the interviewee?
____
____
______

What was her or his demeanor in the interview? (reserved, open, shy, nervous jovial?)____
____
______

What do you think was the most important topic that the interviewee discussed? (to the interviewee)____
____
____
____

How could you tell that this was the most important topic to the interviewee?
____
____
______

Did the person become emotional at any time? (What were they talking about? What emotion were they displaying?)
____
____
______

How do you think the relationship is between the patient and the caregiver? Was there anything that you noticed (that was not said) that told you about the relationship?
____
____
____

Describe the conditions of the home (crowded, dirty, clean, what was it made of, was there furniture)
____
____
____

Describe the condition of the interviewee, did the person appear strong, weak, any skin rashes, what was the person doing when you arrived? ________________
____
____
______

Did you have to work very hard to get the patient to talk? (If so, what did you do to get the patient to talk?)
____
____
____
____

Do you think that the person was telling any lies?
What do you think she or he was lying about?
Why do you think that they were lying?

Do you think that the person was always telling the whole truth? Why do you think that?

Were there a lot of interruptions in the interview?

Can you describe the area where the interview took place?

Do you think that there were people around that could hear the interview?

Can you briefly summarize the important points of the interview?

(what were the comments on **emotional changes**, changes inside the **family,** how the person feels about **socializing**, how he or she deals with **stigma**, how does he or she **compare themselves to others** in the community? What are the person's **future goals**? Are there **any new problems** experienced by the interviewee because of ARV's) (Why is this the most important?)

Demographic Information:
Age: ______
Relationship to Primary Caregiver:_______
Occupation: _________________
Marital Status: _________________
Religion:_____________________
Number of Children: _________
Land Ownership or Rental: _______
Ages and Gender of Children: _____________
Who do these children belong to?________________ ____
Other Household Members (beside caregiver and children):
Construction Material of Home: ______________
Ownership of any means of Communication: (Radio, phone?) __________________
Ownership of any means of Transportation: ___________________________ Ownership of Animals: ____________________
Researcher's Impression of Literacy Level: _____________________-

Appendix C

List of Open Codes Used for Patient Data

Name	Sources	References
ability to accomplish plans for the future	17	39
ability to afford basics-food,transp now	26	85
acceptance	2	2
adherence	18	39
advice to others	16	22
appearance	19	42
Bad death	22	26
being burden to family before drugs	12	14
better off than others	14	35
bewitching	9	9
burdening family after drugs	7	8
can do my work now	25	73
can't work quite as hard as before	17	30
caregivers running away	9	10
certainty of continued health	6	9
change in child's behaviour	1	1
change in expenditures after drugs	10	20
change in family income	2	2
changing priorities	5	7
choosing to die in ignorance	9	11
community perception of recovery- after	13	22
community questions about illness- before	4	6
comparing now to pre illness	14	16
concrete plans for the future after drugs	12	27
consequences of partner's illness	1	3
considering leaving	4	7
continued drug supply	17	28
contradictions	14	34
coping with excessive responsibilities	2	2
death on drugs	20	31
doubting the drugs	4	8
easier to disclose status after drugs	5	10
emotions after, general	24	74
emotions before, general	17	35
example or resource to the community	25	70
faith in God before	9	10
faith in God now	15	23
faith in the drugs	25	82
faith in the government	1	2
family instability after drugs	12	22
family instability before	16	46
family's history with HIV	12	44
fasting for Ramadan	1	1
feeling unsupported after	2	2
feeling unsupported before	5	6
feelings about family instability	3	9
feelings about stigmatiation	19	48

feelings about the clinic	24	52
financial consequences of being sick	16	40
friends who are also on drugs	19	32
general socializing after drugs	27	91
general socializing when sick	19	35
getting cured	7	21
goals for life before sickness	2	2
good quote	22	60
got a girlfriend!	4	5
hiding taking drugs	6	6
HIV has come for everyone	16	28
husband helping me with work of the house	2	4
if they had gotten the drugs	3	3
illness beffore drugs	24	82
impact of illness on family	9	17
important not to worry	15	22
independance	15	28
life with the virus, sick or normal....	24	61
living carelessly	2	2
mzungu drugs	6	14
need to overwork	10	13
no problems	17	34
physical condition after the drugs	26	101
prescence of hope in life now	13	22
questions for us	14	16
random thoughts about life on the drugs	2	4
reaction to testing	15	33
recovery	10	12
regrets	4	5
relationship with children after drugs	11	15
relationship with children before drugs	3	3
relationship with partner after drugs	9	16
relationship with partner before drugs	5	13
relationship with the caregiver after drugs	6	6
relationships within the family	10	24
responsibilities after illness	2	4
responsibilities during illness	4	6
sharing good food	8	10
social pressure on caregiver	2	2
stopping alcohol	6	8
support received after drugs	10	19
support received when sick	15	24
suspicion of HIV	14	27
taking care of myself	5	7
teaching children	16	18
teaching from the clinic	26	57
telling about status or deciding who to tell...	29	100
telling children about status	11	17
telling family about status	3	5
telling partner about status	8	13

testing	22	46
testing partner	10	11
thoughts about being interviewed	8	20
thoughts about future of family after drugs	12	16
thoughts about future of family when sick	14	20
thoughts about sex or reproduction before	4	4
thoughts about sex or reproduction, after drugs	26	54
thoughts of death when sick- constancy,certainty	25	62
thoughts of death-certainty-after	19	31
thoughts on life expectancy	18	21
thoughts on what people think about HIV in general	12	12
thoughts on what people think about these drugs	15	23
thoughts on what people think of my HIV status	19	37
what I want the future to be like, after drugs	29	94
who brought this disease	12	15

List of Selective Codes Used for Patient Data

Type	Name
Level II- Tree Node	events between start of illness and testing

Name	Sources	References
appearance	19	42
Bad death	22	26
being burden to family before drugs	12	14
caregivers running away	9	10
emotions before, general	17	36
family instability before	16	46
feeling unsupported before	5	6
feelings about family instability	4	10
feelings about stigmatiation	19	48
financial consequences of being sick	16	43
general socializing when sick	19	35
impact of illness on family	10	18
relationships within the family	10	24
support received from family when sick	5	6
thoughts about future of family when sick	14	20
thoughts of death when sick- constancy,certainty	25	62
thoughts on what people think about HIV in general	11	11
thoughts on what people think of my HIV status	19	37

Level II- Tree Node

illness and suspicion of HIV

Name	Sources	References
family's history with HIV	13	48
illness beffore drugs	24	82
suspicion of HIV	14	27

Level II- Tree Node

recovery and resolution to crisis

Name	Sources	References
appearance	19	42
general socializing after drugs	27	91
physical condition after the drugs	27	103
prescence of hope in life now	13	22
recovery	10	12
telling partner about status	8	13

thoughts of death-certainty-after	19	31
who brought this disease	12	15

Level II- Tree Node

testing and acceptance of treatment

Name	Sources	References
choosing to die in ignorance	9	11
feelings about the clinic	24	53
friends who are also on drugs	19	32
reaction to testing	15	34
testing	22	46

TREE OF CHANGE CODES

Type	Name
Level II- Tree Node	0utside family socializing

Name	Sources	References
advice to others	16	22
appearance	19	42
better off than others	15	36
choosing to die in ignorance	9	11
example or resource to the community	25	70
feelings about stigmatiation	19	48
general socializing after drugs	27	91
HIV has come for everyone	16	28
telling about status or deciding who to tell...	29	100
thoughts on what people think about HIV in general	12	12
thoughts on what people think of my HIV status	19	37

Level II- Tree Node

death

Name	Sources	References
caregivers running away	9	10
death on drugs	20	31
thoughts of death-certainty-after	19	31
thoughts on life expectancy	18	21

Level II- Tree Node

emotions

Name	Sources	References
appearance	19	

can do my work now	25	73
emotions after, general	24	75
example or resource to the community	25	70
independance	15	28
life with the virus, sick or normal....	24	61
prescence of hope in life now	13	22

Level II- Tree Node	faith in the drugs

Name	Sources	References
adherence	18	39
certainty of continued health		9
continued drug supply	18	29
doubting the drugs		8
faith in the drugs	25	85
getting cured		22
mzungu drugs		14

Level II- Tree Node	money and family

Type	Name
Level III- Tree Node	family

Name	References
burdening family after drugs	8
concrete plans for the future after drugs	27
family instability after drugs	22
family's history with HIV	48
feelings about family instability	10
relationships within the family	24
thoughts about future of family after drugs	17
what I want the future to be like, after drugs	94

Level III- Tree Node	money

Name	References
ability to accomplish plans for the future	39
ability to afford basics-food,transp now	85
concrete plans for the future after drugs	27
financial consequences of being sick	43
what I want the future to be like, after drugs	94

Level II- Tree Node	protecting my delicate health

Name	Sources	References
can't work quite as hard as before	17	30
important not to worry	15	22
need to overwork	10	13
physical condition after the drugs	27	103
sharing good food	8	10
stopping alcohol	6	8

List of Open Codes For Caregivers

Name	Sources	References
ability complete own work when patient sick	11	17
ability to accomplish plans for future	11	17
ability to afford basics after drugs	21	34
ability to afford basics when patient sick	5	6
ability to complete own work now	14	31
acceptance	11	24
advice for others	10	13
asking for help	1	1
attitude that patients need to do well	2	2
bad death	9	9
better off than others	5	7
bewitching	3	4
certainty of death for patient before drugs	12	27
certainty of death for patient now	12	14
certainty of death for self now	5	6
cg-pt relationship as an example to others	3	4
change in expenditures	5	5
choosing to die in ignorance	5	7
community perception of me	5	11
community perception of own status	6	14
community perception of patient's condition before	3	4
community perception of patient's condition-after	4	4
community perception of patient's status	14	26
community perception of people with HIV	9	11
community perception of the drugs	14	17
concern for own future after the drugs	8	10
concern for own future before drugs	11	13
concerns for patient	9	18
concrete plans for the future	3	4
considering leaving the patient	7	13
continued drug supply	9	10
contradiction	8	15
death on drugs	11	15
describing condition of patient now	17	33
describing sickness in patient before drugs	17	28
easier for patient to disclose when healthy	1	1
encouraging patient to care for himself	1	1
encouraging patient to test	6	11
extended family's perception of patient's illness	1	1
faith in the drugs	19	44
family history with HIV	9	22

family instability before drugs	11	14
family instability now	9	11
feeling appreciated	1	3
feeling supported before	14	19
feeling supported now	15	17
feeling unappreciated	3	4
feeling unsupported after drugs	7	16
feeling unsupported-before drugs	13	15
feelings about stigmatization	13	17
feelings about the clinic	2	3
financial consequences of patient's illness	16	27
general feelings after drugs	26	71
general feelings before drugs	21	41
general socializing after the drugs	21	43
general socializing before drugs	10	12
good quote	15	27
having children tested	1	1
hiding taking drugs	1	1
HIV is for everyone	6	9
how change in type of pt's death affects me	1	2
ideas about sex or reproduction after the drugs	8	18
ideas about sex or reproduction before the drugs	3	3
impact of patient's experience on self	2	3
imporant not to worry	7	9
independance	3	3
lessons learnt	10	10
loyalty to the patient	8	12
men's ideas on doing women's work	3	4
muzungu drugs	1	1
need to overwork	1	1
non financial consequences of patient's illness	6	13
own physical condition before drugs	11	19
own physical condition now	8	17
patient or self as an example to others to test	7	11
patient testing	9	12
patient's appearance	3	4
patient's expectations of me	2	3
patient's independance	2	3
peacekeeping responsibilities	4	8
present workload	22	50
questions for us	10	12
reaction to testing results	12	16
relationship with God	9	12
relationship with partner before drugs	4	11
relationship with partner now	6	20
relationship with patient	11	25
sharing good food	9	10
special care for the patient- after drugs	20	46
suspicion of HIV in pt	7	12
suspicion of own status	6	8

teaching children	4	4
teaching from the clinic	15	29
telling children	8	8
telling others about own status	8	16
telling others about patients status	19	32
telling partner	1	1
tension in the home-family relations	7	20
testing self	11	17
thoughts about future of family now	3	5
thoughts about future of family when patient sick	12	16
thoughts about how other people hide status	1	1
thoughts of patient's life expectancy	15	18
thoughts on being interviewed	9	12
thoughts on life expectancty for self	2	2
wanting to get self tested	8	9
what i want future to look like	18	44
what I want to learn from patient	1	2
what it woul be like if I tested positive	1	1
who brought this disease	5	11
whose life has priority	6	6
why I care for the patient	13	21
work load when patient was sick	24	48
working together or what the patient contributes now	18	37

List of Selective Codes For Caregivers

Name
LEVEL I-CONTEXT

Type	Name
LEVEL II Node	considering leaving and why I care

Name	Sources	References
acceptance	11	24
community perception of me	8	19
considering leaving the patient	9	16
why I care for the patient	16	34

Type	Name
LEVEL II Node	family instability

Name	Sources	References
family history with HIV	10	23
family instability before drugs	13	16
tension in the home-family relations	8	21

Type	Name
LEVEL II Node	feelings and socializing before

Name	Sources	References
feeling supported before	16	21
feeling unsupported-before drugs	15	18
general feelings before drugs	23	51
general socializing before drugs	11	14
thoughts about own and family's future when patient sick	17	25

Type	Name
LEVEL II Node	responsibilities when patient sick

Name	Sources	References
ability complete own work when patient sick	14	21
financial consequences of patient's illness	20	39
own physical condition before drugs	13	21
work load when patient was sick	26	61

Name
LEVEL I NODE-CHANGES AFTER HAART

Type	Name
LEVEL II NODE	continued care for the patient

Name	Sources	References
concerns for patient after drugs	13	30
encouraging patient to care for himself	1	1
imporant not to worry	7	9
special care for the patient- after drugs	21	49

LEVEL II Node	feelings and socializing after

Name	Sources	References
community perception of me	8	19
feeling supported now	16	19
feeling unsupported after drugs	7	16
feelings about stigmatization	14	18
general feelings after drugs	28	87
general socializing after the drugs	22	44
thoughts about future of self and family now	13	22

LEVEL II- Node	present workload

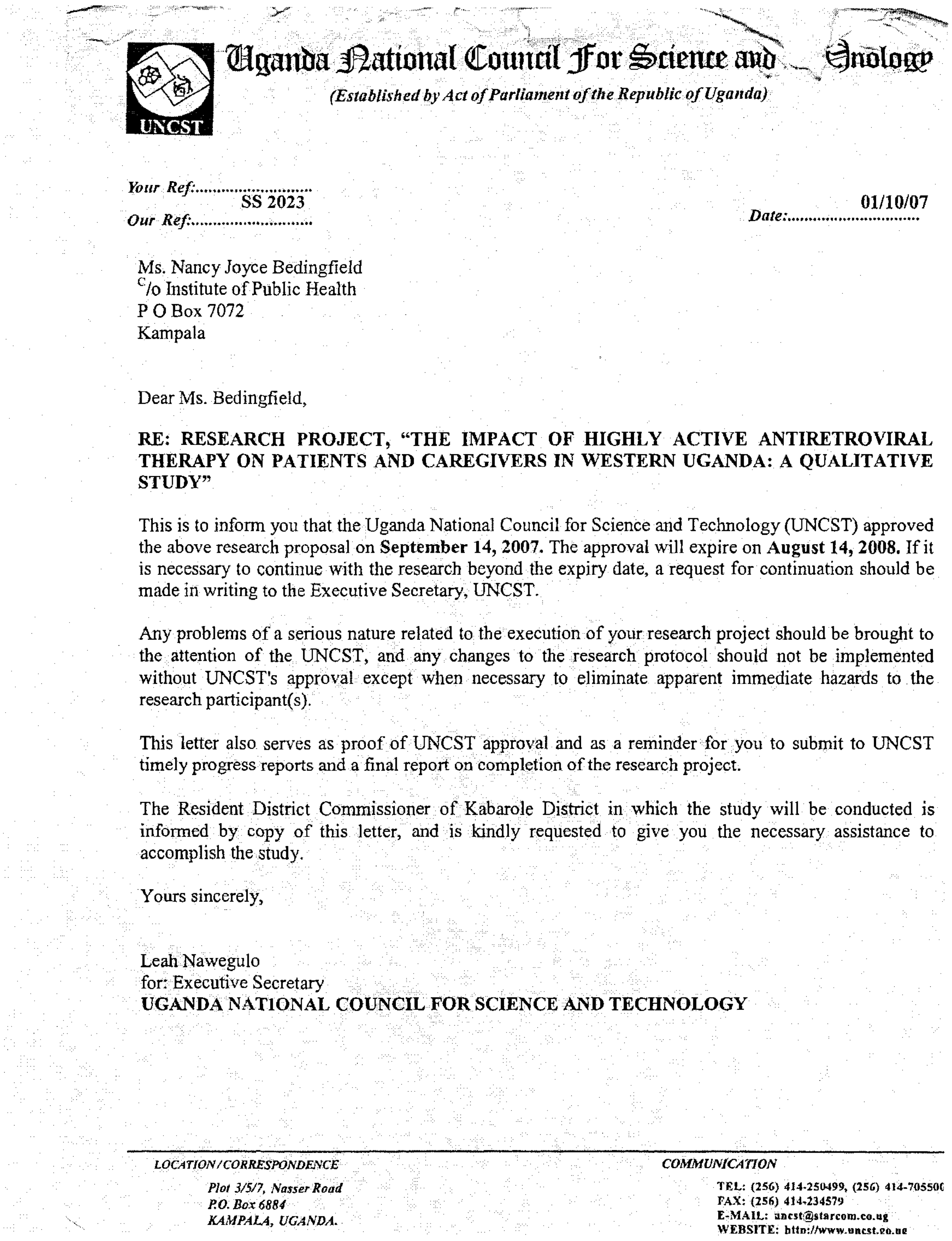
Name	Sources	References
ability to complete own work now	15	35
present workload	24	59
working together or what the patient contributes now	20	47

LEVEL I- COMMONALITIES WITH PATIENTS

Type	Name	Sources	References
LEVEL II Node	bad death	10	12
LEVEL II Node	certainty of death for patient before drugs	14	33
LEVEL II Node	certainty of death for patient now	14	16
LEVEL II Node	community perception of patient's status	16	31
LEVEL II Node	continued drug supply	10	11
LEVEL II Node	death on drugs	12	18
LEVEL II Node	faith in the drugs	21	50
LEVEL II Node	financial consequences of patient's illness	20	39
LEVEL II Node	telling others about patients status	20	33
LEVEL II Node	What i want future to look like	20	51

Appendix D

Ugandan Ethics Approval



UNCST
Uganda National Council For Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

Your Ref:............................
Our Ref: SS 2023

Date: 01/10/07

Ms. Nancy Joyce Bedingfield
C/o Institute of Public Health
P O Box 7072
Kampala

Dear Ms. Bedingfield,

RE: RESEARCH PROJECT, "THE IMPACT OF HIGHLY ACTIVE ANTIRETROVIRAL THERAPY ON PATIENTS AND CAREGIVERS IN WESTERN UGANDA: A QUALITATIVE STUDY"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **September 14, 2007.** The approval will expire on **August 14, 2008.** If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

The Resident District Commissioner of Kabarole District in which the study will be conducted is informed by copy of this letter, and is kindly requested to give you the necessary assistance to accomplish the study.

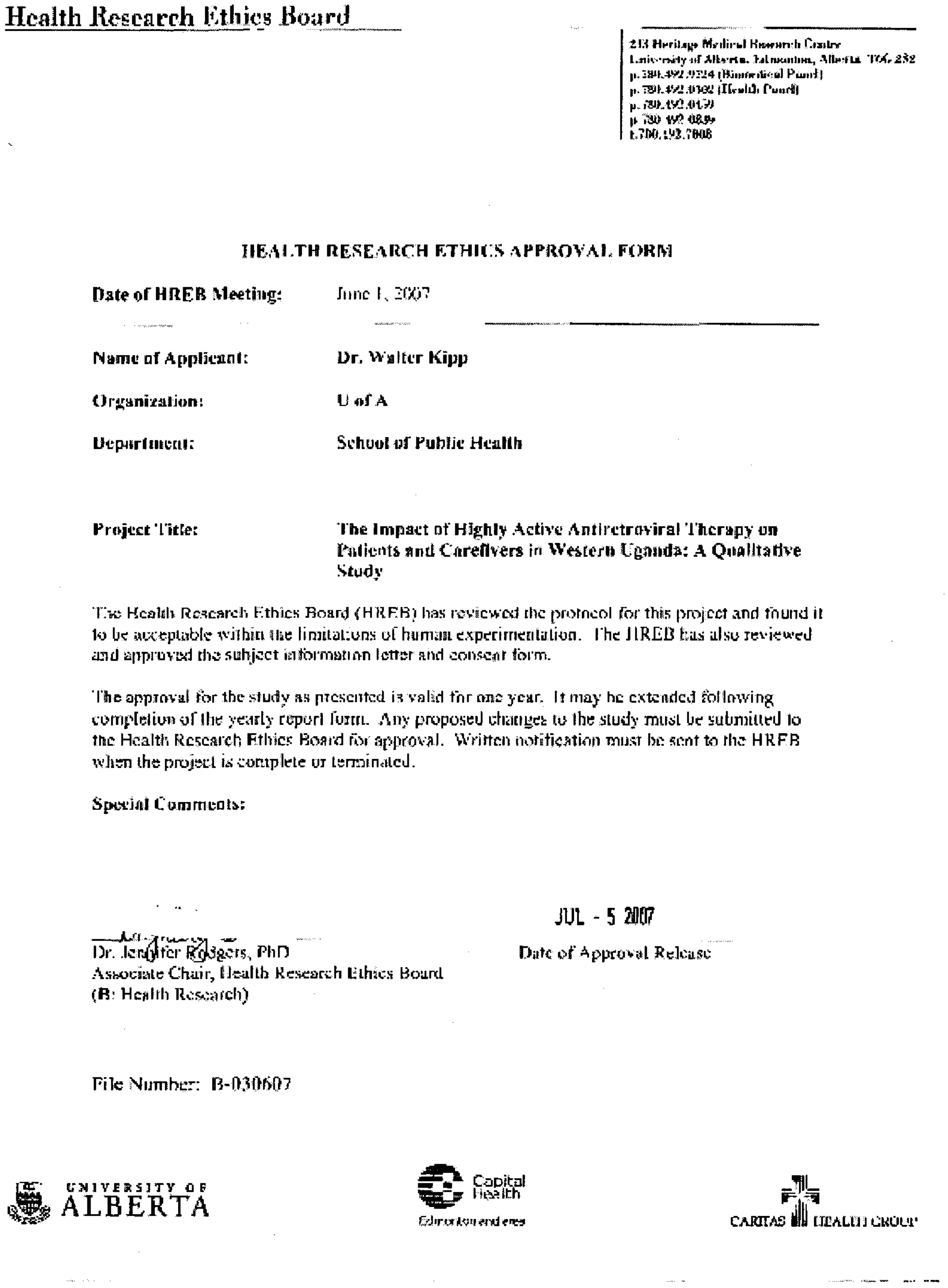
Yours sincerely,

Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE
Plot 3/5/7, Nasser Road
P.O. Box 6884
KAMPALA, UGANDA.

COMMUNICATION
TEL: (256) 414-250499, (256) 414-705500
FAX: (256) 414-234579
E-MAIL: uncst@starcom.co.ug
WEBSITE: http://www.uncst.go.ug

University of Alberta Ethics Approval



Health Research Ethics Board

213 Heritage Medical Research Centre
University of Alberta, Edmonton, Alberta T6G 2S2
p.780.492.9724 (Biomedical Panel)
p.780.492.0302 (Health Panel)
p.780.492.0459
p.780.492.0839
f.780.492.7808

HEALTH RESEARCH ETHICS APPROVAL FORM

Date of HREB Meeting:	June 1, 2007
Name of Applicant:	**Dr. Walter Kipp**
Organization:	**U of A**
Department:	**School of Public Health**
Project Title:	**The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study**

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Special Comments:

Dr. Jennifer Rodgers, PhD
Associate Chair, Health Research Ethics Board
(B: Health Research)

JUL - 5 2007
Date of Approval Release

File Number: B-030607

UNIVERSITY OF ALBERTA

Capital Health
Edmonton and area

CARITAS HEALTH GROUP

Appendix E
Information Letters

All information Letters were translated into Rutooro and distributed on University of Alberta Letterhead. Translation of information letters was verified by a third party.

Caregivers Group Interview

The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study

Principal Investigator: Walter Kipp Co-Investigator: Nancy Bedingfield
Professor Masters of Science
Candidate, Global Health
School of Public Health, University of Alberta School of Public Health,
University of Alberta
Edmonton, AB. **Walter.kipp@ualberta.ca, (780) 492-864** Edmonton, AB,
nbedingf@ualberta.ca

Why is this study being done?: You are being asked to be in a research study that will help us learn more about how people's lives change when a person that they care for has started taking Highly Active Antiretroviral Treatment (HAART). We hope that this information will help people who run HAART programs to be able to help people like you better.

What you will have to do: If you would like to join the study we will talk to you together with other people. **All of the other people will be caregivers for people taking HAART**. It will take about one and a half hours. **If it is okay with you, we would like to tape record what is said.** We will pay for you to get to the place that everyone will meet to talk. We will ask if your feelings have changed since your loved one has started the medication. We would like to know about your worries and thoughts about the future. We would also like to know if you are spending time with other people differently now.

What good things could happen if you join the study: It may help you to talk about some of the changes that have been happening in your life. It may also help the people who run the Community Based Antiretroviral Treatment for AIDS Patients Program to help you more to deal with your worries.

What bad things could happen if you join the study: It may make you upset to think back to when your loved one was sick or into the future when that person may die. We do not know of any other bad things that could happen. It is very important that you know that nothing you do that involves this study can affect the medication supply of the person that you care for. If you do not participate he or she will still get the medications and if you say bad things about the medications or the program, he or she will still get the medications.

Who will know what you have said to us: **It is important that you do not share information that you have learned about other members of the group with people outside of the group. This will protect everyone's privacy. The Researcher and the Researcher's Assistant will try very hard to protect your privacy. We cannot promise that others in the group will also do this. The group discussion may be talked about in the research, but your name will not be used. Any papers with your names on it will be locked away for five years and then destroyed.**

Can I stop being in the study whenever I want? Yes. You do not have to agree to start the study and if you want to stop being in the study at any time, you can. **If there are certain questions that you don't want to answer that is also OK. This will not affect your loved one's supply of medication.**

Who can answer my questions about this study? You can call Nancy Bedingfield at ?(**cell number to be obtained in Uganda**) or Tom Rubaale at the Health Department in Fort Portal at 0782-856-865

Patient Group Interview

The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study

Principal Investigator: Walter Kipp
Professor
Global Health
School of Public Health, University of Alberta
Edmonton, AB, walter.kipp@ualberta.ca, **(780) 492-8643**

nbedingf@ualberta.ca

Co- Investigator: Nancy Bedingfield
Masters of Science Candidate,

School of Public Health, University of Alberta
Edmonton, AB,

Why is this study being done?: You are being asked to be in a research study that will help us to learn more about how people's lives change after starting Highly Active Antiretroviral Treatment (HAART). We hope that this information will help people who run HAART Programs to help people like you better.

What you will have to do: If you join the study, we will ask you some questions **and talk to you together with other people taking HAART**. It will take about one and a half hours. **If it is okay with you, we would like to tape record what is said.** We will pay for you to get to the place that everyone will meet to talk. We will ask if your feelings have changed since you started the medication. We will also ask you about your worries and thoughts about the future. We would also like to know about how you spend time with other people.

What good things could happen if you join the study: It may help you to talk about some of the changes that have been happening in your life. It may also help the people who run the Community Based Antiretroviral Treatment for AIDS Patients Program to help you more to deal with your worries.

What bad things could happen if you join the study: It may make you upset to think back to when you were sick or into the future when you may die. We do not know of any other bad things that could happen. It is very important that you know that nothing you do that involves this study can affect your medication supply. If you do not participate you will still get the medications and if you say bad things about the medications or the program, you will still get the medications.

Who will know what you have said to us: **It is important that you do not share information that you have learned about other members of the group with people outside of the group. This will protect everyone's privacy. The Researcher and the Researcher's Assistant will try very hard to protect your privacy. We cannot promise that others in the group will also do this. The group discussion may be talked about in the research, but your name will not be used. Any papers with your names on it will be locked away for five years and then destroyed.**

Can I stop being in the study whenever I want? Yes. You do not have to agree to start the study and if you want to stop being in the study at any time, you can. **If there are certain questions that you do not want to answer that is okay. This will not affect your medication supply.**

Who can answer my questions about this study? You can call Nancy Bedingfield at ?(**cell number to be obtained in Uganda**) or Tom Rubaale at the Health Department in Fort Portal at 0782-856-865

Patient Individual Interview

The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study

Principal Investigator: Walter Kipp
Professor
School of Public Health, University of Alberta
Edmonton, AB, **Walter.kipp@ualberta.ca (780) 492-8643**

Co- Investigator: Nancy Bedingfield
Masters of Science Candidate, Global Health
School of Public Health,
University of Alberta
Edmonton, AB, **nbedingf@ualberta.ca**

Why is this study being done?: You are being asked to be in a research study that will help us learn more about how people's lives change after starting Highly Active Antiretroviral Treatment (HAART). We hope that this information will help the people who run HAART Programs to help people like you better.

What you will have to do: If you join the study we will ask you some questions about your life. We would like to talk to you two different times. It will take about one and a half hours each time. **If it is okay with you, we would like to tape record what is said.** You can choose if you would like to talk to us at your house or in another place. If you would like to talk to us in another place, we will pay for you to get to that place. We will ask if your feeling have changed since you started the medication. We will also ask you about your worries and thoughts about the future. We would also like to know about how you spend time with other people.

What good things could happen if you join the study: It may help you to talk about some of the changes that have been happening in your life. It may also help the people who run the Community Based Antiretroviral Treatment for AIDS Patients Program to help you better.

What bad things could happen if you join the study: It may make you upset to think back to when you were sick or into the future when you may die. It is also possible that having stranger visit your home will may people wonder if you have HIV. We do not know of any other bad things that could happen. It is very important that you know that nothing you do in this study can affect your medication supply. If you do not participate you will still get the medications. If you say bad things about the medications or the program, you will still get the medications.

Who will know what you have said to us: We will not use your name in the study. **Only the researcher and the Researcher's Assistant will know that it was you who said these things.** The things that you say may become public, but no one will ever know that it was you who said it, even the people who run the program. All of the papers that have your name on it will be locked away for five years and then destroyed.

We will also try to talk with the person who cares for you, but they will not know what you have said to us.

Can I stop being in the study whenever I want? Yes. You do not have to agree to start the study. If you want to stop being in the study at any time, you can. **It is OK if there are some questions that you don't want to answer. This will not affect your supply of medication.**

Who can answer my questions about this study? You can call Nancy Bedingfield at ?(**cell number to be obtained in Uganda**) or Tom Rubaale at the Health Department in Fort Portal at 0782-856-865

Individual Caregiver Interview

The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study

Principal Investigator: Walter Kipp
Professor
School of Public Health, University of Alberta
Edmonton, AB, **Walter.kipp@ualberta.ca** **(780) 492-8643**

Co- Investigator: Nancy Bedingfield
Masters of Science Candidate, Global Health
School of Public Health,
University of Alberta
Edmonton, AB, **nbedingf@ualberta.ca**

Why is this study being done?: You are being asked to be in a research study that will help us to learn more about how people's lives change when a person that they care for starts taking Highly Active Antiretroviral Treatment (HAART). We hope that this information will help the people who run HAART programs to help you people like you better.

What you will have to do: If you join the study we will ask you some questions about your life. We would like to talk to you two different times. It will take about one and a half hours each time. **If it is okay with you, we would like to tape record what is said**. You can choose if you would like to talk to us at your house or in another place. If you would like to talk to us in another place, we will pay for you to get to that place. We will ask if your feelings have changed since your loved one has started the medication. We would also like to know about your worries and thoughts about the future. We would also like to know if you are spending time with other people differently now.

What good things could happen if you join the study: It may help you to talk about some of the changes that have been happening in your life. It may also help the people who run the Community Based Antiretroviral Treatment for AIDS Patients Program to help you better.

What bad things could happen if you join the study: It may make you upset to think back to when your loved one was sick or into the future when that person may die. It is also possible that having a stranger visit your home will may people wonder someone in the house has HIV. We do not know of any other bad things that could happen. It is very important that you know that nothing you do that involves this study can affect the medication supply of the person that you care for. If you do not participate they will still get the medications. If you say bad things about the medications or the program, they will still get the medications.

Who will know what you have said to us: **We will not use your name in the study. Only the Researcher and the Researcher's Assistant will know that it was you who said these things.** The things that you say may become public, but no one will ever know that it was you who said it, even the people who run the program. All of the papers that have your name on it will be locked away for five years and then destroyed.

We will also interview the person that you are caring for about the changes in their lives. The person that you care for will not know what you have said to us.

Can I stop being in the study whenever I want? Yes. You do not have to agree to start the study. If you want to stop being in the study at any time, you can. **It is also OK if there are certain questions that you do not want to answer. This will not affect your loved one's supply of medication**

Who can answer my questions about this study? You can call Nancy Bedingfield at ?(**cell number to be obtained in Uganda**) or Tom Rubaale at the Health Department in Fort Portal at 0782-856-865

Child Assent Form

The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study

Principal Investigator: Walter Kipp
Professor
School of Public Health, University of Alberta
Edmonton, AB, **Walter.kipp@ualberta.ca (780) 492-8643**

Co- Investigator: Nancy Bedingfield
Masters of Science Candidate, Global Health
School of Public Health,
University of Alberta
Edmonton, AB, **nbedingf@ualberta.ca**

Why is this study being done? We are doing a study to find out how things have changed in your life for you since your Mom or Dad has started HAART (Highly Active Antiretroviral Treatment).

What you will have to do: If you would like to join the study we will ask you some questions about your life. We would like to talk to you two different times. It will take about one and a half hours each time. **If it is okay with you, we would like to tape record what is said.** You can choose if you would like to talk to us at your house or in another place. If you would like to talk to us in another place, we will pay for you to get to that place. We will ask you about your feelings since your Mom or Dad has started the medication. We will also ask you about your worries and your thoughts about the future. If there have been any changes to how much you see your friends, we would also like to talk about that.

What good things could happen if you join the study: It may help you to talk about some of the changes that have been happening in your life. It may also help the people who run the Community Based Antiretroviral Treatment for AIDS Patients Program to help you better.

What bad things could happen if you join the study: It may make you upset to think back to when your Mom or Dad was sick or into the future when your Mom or Dad may die. It is also possible that having a stranger visit your home may make people wonder if someone in your house has HIV. We do not know of any other bad things that could happen. It is very important that you know that nothing you do with this study can affect your Mom or Dad's medication. If you do not participate they will still get the medications. If you say bad things about the medications or the program, they will still get the medications.

Who will know what you have said to us: **No one will know what you have said except for the Researcher and the Researcher's Assistant.** It is OK if you do not want to say anything at all to us. Other people may read about what you have said, but they will never know that this was you. **We will also interview your Mom or Dad. They will not know what you have said to us.**

Can I stop being in the study whenever I want? Yes. You do not have to agree to start the study. If you change your mind and want to stop being in the study, you can stop any time. **It is also OK not to answer certain questions. That will also not affect you Mom or Dad's supply of medication.**

Let's stop now and talk about your questions. If you have more questions you can call these people; Nancy Bedingfield? (**Cell number to be obtained in Uganda**), or Tom Rubaale at 0782-856-865
I agree to take part in the study

________________________ Signature or thumbprint of child//date ____________________
________________________ Signature of Research Assistant//date ____________________

Appendix F

All forms were translated into Rutooro and verified prior to distribution.

Consent Form

Title: The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study
Principal Investigator: Nancy Bedingfield, University of Alberta, Canada//Mobile: Ugandan cell
Co investigator: Dr. Walter Kipp, University of Alberta, Canada //Phone: 1(780)492-8643

Part 2: Consent of Subject

	Yes	**No**
Do you understand that you have been asked to be in a research study?		
Have you read or has someone read to you the Information Sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had a chance to ask questions and discuss this study?		
Do you understand that you are free to stop being in the study at anytime and for no reason?		
Do you understand who will be able to see this information once it is collected said?		

Part 3: Signatures

This study was explained to me by: ______________________________

Date (dd/mm/yyyy):: ____________________

I agree to take part in this study. Yes ☐ No ☐

Name of Research Participant (*print*):

____

Signature (or Thumbprint) of Research Participant:

____

Thumbprint Here:

Witness : ______________________________

Witness Signature (or Thumbprint):

____

Thumbprint Here:

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee: ______________________________

Date Consent Received (dd/mm/yyyy): ____________________

The Information Sheet must be attached to this Consent Form and a copy given to the research subject

Parental Consent Form

(Parent also given Information letter which was given to the child)

The Impact of Highly Active Antiretroviral Therapy on Patients and Caregivers in Western Uganda: A Qualitative Study

Principal Investigator: Walter Kipp
Professor
School of Public Health, University of Alberta
Edmonton, AB, **Walter.kipp@ualberta.ca** **(780) 492-8643**

Co- Investigator: Nancy Bedingfield
Masters of Science Candidate, Global Health
School of Public Health,
University of Alberta
Edmonton, AB, **nbedingf@ualberta.ca**

Part 2 Consent of the Subject

Do you understand that your child has been asked to be in a research study?	**Yes**	**No**
Have you read or listened to a copy of the Information sheet?		
Do you understand the risk and benefits to your child of being in the study?		
Have you had the opportunity to ask questions?		
Do you understand that you are free to stop the interview with your child at any time and for no reason?		
Do you understand who will be able to see this information after it is collected?		

What is the name of the person who explained this to me

____

Date ____________

I agree for my child to take part in this study yes______________ No_________

Signature of Parent ___________________________________ Date _____________

Signature of Research Assistant __________________________ Date _____________

Signature of Witness ___________________________________ Date _____________

RESEARCH ASSISTANT CONFIDENTIALITY AGREEMENT

COMMUNITY BASED ARV PROJECT
KABAROLE DISTRICT, UGANDA

In consideration of my employment to work on the Community-Based ARV Project:

1. I agree to keep all information concerning the project, including all information collected by me for this project confidential.
2. I will collect, access, use, destroy or disclose confidential information only within the scope of my official position and normal responsibilities.
3. I will not remove any confidential information from the designated project offices without permission from my supervisor.
4. I will not create any false record as part of my duties under the project.
5. At the end of my employment, I will continue to treat all information of the project as confidential and I will immediately return all documents and/or materials belonging to the project.

I understand that failing to comply with the above requirements may result in disciplinary action including loss privileges, or termination of my employment.

I acknowledge that the terms of this Confidentiality Agreement will survive the expiry of my employment with the project, and that the project reserves the right to seek prosecution of an individual committing an infraction of the terms of this Agreement, regardless of the individual's present status of employment.

Signed:____________________________________ Date:______________

Print
Name:____

______

(First, & Last Name)

For Project Manager: